

DEPARTMENTS OF LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES
APPROPRIATIONS FOR 2011

HEARINGS
BEFORE A
SUBCOMMITTEE OF THE
COMMITTEE ON APPROPRIATIONS
HOUSE OF REPRESENTATIVES
ONE HUNDRED ELEVENTH CONGRESS
SECOND SESSION

SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND
HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

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Minority Member of the Full Committee, are authorized to sit as Members of all Subcommittees.

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PART 6
STATEMENTS OF MEMBERS OF CONGRESS AND OTHER
INTERESTED INDIVIDUALS AND ORGANIZATIONS



Printed for the use of the Committee on Appropriations

Part 6

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AND RELATED AGENCIES APPROPRIATIONS FOR 2011**

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**DEPARTMENTS OF LABOR, HEALTH AND
HUMAN SERVICES, EDUCATION, AND RE-
LATED AGENCIES APPROPRIATIONS FOR
2011**

WEDNESDAY, MAY 12, 2010.

TESTIMONY OF INTERESTED INDIVIDUALS AND
ORGANIZATIONS

CHAIRMAN'S OPENING STATEMENT

Mr. OBEY. Well, good morning, everybody. Let me apologize for being late and to make just a couple comments about what we are going to be doing here today.

I appreciate the fact that everyone who testifies today is going to be here in earnest support of programs that they think are vital. I spent a good deal of time last night looking over the statements of all of the witnesses for this morning and this afternoon, and I have to say that I agree with virtually all of them.

But there is a problem. If you total up the cost of all of the items that are being requested in these statements, we wind up with requests that we increase the President's budget by almost \$14 billion and I think that, on the merits, is needed when it comes to health care research or when it comes to education. But when it comes to worker protection, I am a big spender and I make no apology for it.

But we do have a problem because we have, even though the President asked for a budget freeze, we have the Republican leadership asking that we cut deeper than that; we have blue dog Democrats who are also asking that we cut deeper than that.

In fact, if you take a look at the budget levels that we are going to be forced to operate under, we will not be able to increase this bill by \$14 billion as a lot of you are going to be asking today; we are going to have to cut this bill by about \$3.5 billion. And that means \$3.5 billion below Obama's budget. And the reason for that, frankly, is that the Country, and many members in the Congress, are apparently fixated only on one deficit, the Federal budget deficit. And I agree that is an important problem that must come down over time, once the economy starts to recover.

But we have other deficits, as the testimony here today will certainly demonstrate. We have opportunity deficits, we have health care deficits, we have education deficits, we have science deficits; and those will not be responded to to any great degree unless there

is a significant mind-set in the Country and a significant mind-set in the Congress.

That is one of the reasons why I am leaving Congress, because I am tired of producing bills that are inadequate to meet the needs of the Country, and yet the Congress and past presidents have not been at all bothered to increase the size of those deficits by providing very large tax cuts by financing, in my view, a misbegotten war.

So I know some people will say, well, yeah, but you can fit my program in, you just have to cut some other fellow's program. And it is because of that response that I have had hanging on my wall for the last eight years this sign. As you can see, it is elegant and beautiful. What it says is: What do you want me to do for somebody besides yourself that is more important than whatever it is you want me to do for you? Because that is the spirit that we have to move forward in if we are going to deal with budgets in a rational way.

So I do not by any means want to discourage any of you from testifying today. What you will ask for is certainly needed; I recognize that. But I hope that you recognize that we need one hell of a lot of help to convince the public that we do the Country no favors when we short-sheet crucial long-term investments in health care, education, worker protection, environmental protection, and the like.

We came out of the wilderness as a backward Country, and in the 19th century, because this Country made the right investments, by the beginning of the 20th century we became a worldwide powerhouse; and we did that by making the right kind of investments in the right things.

So I apologize ahead of time to all of you for the limitations of the budget that we will be able to produce this year because of the factors that I have just described. And if you want to change that so that we do not have to, in the future, or so that people in the future, who are sitting in this chair, do not have to cut bills that they do not want to cut, then you have to go back home to your neighbors and make them understand that we are not going to be a great Country if we recognize the cost of everything and the value of nothing.

So thank you for listening while I spout off.

Mr. Tiahrt is not here.

Denny, would you like to say anything in response before we begin?

RANKING MEMBER'S OPENING STATEMENT

Mr. REHBERG. Well, let me just begin by saying, Mr. Chairman, thank you for your service on the Subcommittee. I do not get to be Acting Ranking very often, so I do not want to miss the opportunity to just say a few words to you, and that is I have appreciated everything you have done, both for this Subcommittee and the full Committee.

I was sitting here reminiscing a bit while you were speaking. The last CODEL I took was with Mr. Murtha, Mr. Hobson, Mr. Walsh, and yourself, and I am the last man standing. That makes me a little nervous.

But it has been an educational experience, and serving on all the subcommittees that I do and have, this is the most meaningful exercise that any of the Subcommittees does, by bringing in a number of people to, in a rapid fashion, tell us their needs and give us a little glimpse of their organization and their desires of building a more secure future for the people that they represent.

So I appreciate the process and I appreciate your leadership. We are going to miss you a lot. If you would be so kind, I would adopt Archie the Cockroach: "And if I have anything to say about it, we will get rid of the pencils; I do not think we need anything with an eraser on it." But thanks for your kind service and an opportunity to thank you publicly, and why do we not begin?

Mr. OBEY. Thank you. Thank you very much.

All right, first we have Brigadier General Billy Cooper, representing the National Job Corps Association.

And let me say that we are going to have to strictly enforce the four minute time limit, or the people at the back end of the schedule will not get a chance to testify. I am also concerned we are going to be interrupted by roll calls on the House Floor. The Congress would work just fine if we did not have to interrupt our work to go vote. [Laughter.]

Mr. OBEY. Proceed.

WEDNESDAY, MAY 12, 2010.

JOB CORPS

WITNESS

**BRIGADIER GENERAL (RET.) BILLY COOPER, CENTER DIRECTOR,
EARLE C. CLEMENTS JOB CORPS CENTER, NATIONAL JOB CORPS
ASSOCIATION, DEPARTMENT OF LABOR**

General COOPER. Mr. Chairman, members of the Subcommittee, thank you for this opportunity to talk about a passion of mine and thousands of other professionals around the Country, which is Job Corps. I am Billy Cooper. As you indicated, I am a retired Brigadier General from the United States Army, and currently I am the Center Director for the second largest Job Corps Center in the Country, in Morganfield, Kentucky, the Earle C. Clements Center.

Before I get started, I would like to thank you for championing Job Corps throughout your illustrious service. As you know, in the very near future, we are going to open the new center in Wisconsin, and I look forward to meeting you there when we have an opportunity to open that one.

My journey to Job Corps was not typical. While I do hold a Master's Degree in Education, I did not start out as an educator; I am a Vietnam draftee who ascended to the rank of Brigadier General and had an opportunity to live the American dream by virtue of service in our armed forces. And my goal is to try to figure out how to help young men and women today to understand that the American dream is still possible; they can live it, but it is going to take some hard work, some education, some job training, and an opportunity that will only exist for them in America.

I first learned about Job Corps when I was serving as the Deputy Commanding General of the U.S. Army Recruiting Command at

Fort Knox. There, I was introduced to the dozens of unique and holistic services that Job Corps has to offer to disadvantaged youth, and I became a believer in the program. I was responsible for starting a partnership between Job Corps and the Army which enhances the opportunity for young men and women who attend Job Corps to enlist in our armed forces today, and that agreement is still intact.

Nine years ago, I could have gone into a very comfortable retirement, but I chose to serve my Country again through Job Corps. Like so many and you, we saw that the youth in America today might have had an opportunity to miss out on the American dream, and that is why Job Corps exists.

I left the military, became a Center Director, and Job Corps, unlike many programs I encountered in the military, does in fact teach young men and women to be all that they can be through the comprehensive services that Job Corps provides.

Job Corps is the only viable option for thousands of disadvantaged youth. They enroll voluntarily. It is difficult for a young man or woman to learn when they are hungry, when they are homeless, when they live in poverty and really cannot see a way out. The promising news is that, with a modest investment in fiscal year 2011, Mr. Chairman, Job Corps can cost-effectively use its existing facilities to serve additional needy youth.

Secondly, Job Corps offers comprehensive services, which include health care, dental care, education through college, job training, counseling; and we have Job Corps Centers in almost 50 States today. We have 123 and the Wisconsin Center will be number 124.

On average, I welcome 40 new students to my Center every Tuesday. As I said, they are volunteers, and instead of dropping out of society in general, they come to Job Corps to get a second chance. We provide healthy meals, nutrition counseling, counseling, education, and job training again. And for members of the Subcommittee, I simply want to say it is the only program that provides these comprehensive services.

Do not just take my word for it. Before I run out of time, I would like to introduce one of my students—

Mr. OBEY. [Remarks made off microphone.]

General COOPER. Well, instead of having Mr. Brooks testify, I will tell you he dropped out of high school. He was from Oakland originally; he is from Florida now. He had an opportunity to hit the mean streets, but did in fact choose to help his family by coming to Job Corps, where he has earned his skill certification in electricity, will complete his high school diploma within the next couple of months. Instead of being a liability to society, he will in fact be an asset. Serves as a role model. He is probably going to go on to college when he leaves Job Corps; we believe we can get him a music scholarship at Kentucky State University. He is a great alto saxophonist and a super young man, and I regret that you did not have an opportunity to hear his entire story.

Mr. OBEY. I do too, especially if he is a musician. I like bluegrass and play it myself. [Laughter.]

But we are going to have to move on.

And let me say, do not take the lack of comments or questions from people on the panel as disinterest. We get plenty of time to

talk to each other, but if we do not shut up today, we will never get through all of the witnesses that we have.

Thank you much.

General COOPER. Thank you, sir, for your service and my opportunity to testify before the Committee.

[Written statement by Billy Cooper follows:]



**Testimony
before the U.S. House of Representatives
Subcommittee on Labor, Health and Human Services and
Education Appropriations**

**Brigadier General (retired) Billy Cooper, Center Director,
Earle C. Clements Job Corps Center
May 12, 2010**

Mr. Chairman, members of the Subcommittee, thank you for this opportunity to talk about a true passion of mine and thousands of other dedicated educators and professionals across the country – Job Corps. My name is Billy Cooper, retired Brigadier General, and currently the center director at the Earle C. Clements Job Corps Center in Morganfield, Kentucky.

Before I get started, I would like to thank Chairman Obey – on behalf of the entire Job Corps community – for your longtime support and advocacy of Job Corps. You have been a champion of Job Corps for many years and you will be sorely missed. It will be very soon that Job Corps welcomes the Milwaukee facility into the family, and it wouldn't have happened without your commitment to Job Corps. We hope that you will join us when we officially open the doors of Job Corps to hundreds of Wisconsin youth!

My journey to Job Corps was not typical. While I do hold a master's degree in education administration, for most of my adult life I was not an educator. I was a soldier first. As a Vietnam veteran, I was called to proudly serve my country and was fortunate to have a lasting military career that sent me around the U.S. and abroad. I served in a wide-range of positions and earned recognition and decorations. I lived the American dream.

However, it was when I first learned about Job Corps that I knew what my true calling was – instilling the courage and confidence today's young people need to begin their own career path. Prior to my retirement from the military in 2001, I served as the Deputy Commanding General of the U.S. Army Recruiting Command. There I was introduced to the dozens of unique and holistic services Job Corps offers to our nation's most economically disadvantaged youth. It was then that I became a believer. I was determined to develop a national partnership between the U.S. Army and Job Corps that I am proud to say still exists today.

Nine years ago it would have been easy for me to transition into a comfortable civilian life; however, I was called to serve my country again. Like you, I saw that so many of today's young people desperately need to believe that the American dream is still possible. I left the military and became a center director. Job Corps, unlike other programs I encountered while in the military, teaches, prepares and helps youth be all they can be with all of the support they need. Why do I say this?

(1) Job Corps is the only viable option for thousands disadvantaged youth. Many of America's most vulnerable youth desperately need a safe living and learning environment. Homeless teens, high school dropouts, young mothers and fathers, youth aging out of the foster care system and countless more youth have no place to go. They enroll in Job Corps because it offers everything they do not have. A young man or woman can't learn if he/she has no place to live. A young man or woman can't learn if he/she is hungry. A young man or woman can't learn if he/she lives in poverty with no end in sight. The promising news is that, with a modest investment in fiscal year 2011, Mr. Chairman, Job Corps can cost-effectively use its existing facilities to serve additional needy students.

(2) Job Corps offers comprehensive services to our nation's most vulnerable youth. At my Job Corps center, and the 123 others located in nearly all 50 states, we provide students an array of services to put them on a path to a career, higher education or the military. I, on average, welcome 40 new Job Corps students to my campus every Tuesday. It is a humbling experience to recognize that these youth are a turning point in their lives. They could have lost all hope because of their circumstances. Instead, they chose to voluntarily enroll in Job Corps. Upon enrollment, these youth are provided housing, three healthy meals day, basic medical and dental services, education and training, mentoring, counseling and job placement. Additionally, Job Corps students participate in extracurricular activities to become well-rounded individuals. They gain leadership and conflict resolution skills, diversity appreciation, community service opportunities, and even Job Corps' version of First Lady Michelle Obama's "Let's Move" campaign. Mr. Chairman and other members of the Subcommittee, Job Corps' comprehensive services are essential to not only prepare these youth for a job or whatever path they choose, but also to give them the courage and confidence to do anything they set their minds to.

(3) Job Corps works and is worth the investment. Over 45 years the Department of Labor has honed Job Corps' comprehensive model for preparing out-of-school, out-of-work youth for jobs, higher education or a military career. Studies have shown this model to be among the most effective. A federal study undertaken to evaluate various federal interventions for disconnected youth found that Job Corps had the most significant impacts on participants' education achievement and earnings. This is because Job Corps comprehensively addresses what America's impoverished youth face. In 9 – 10 short months, Job Corps' staff work with students to help them achieve goals they once through were out of their reach. Consider this:

- 75% of our students are high school dropouts, and because of Job Corps the majority leave with a high school diploma or GED.
- 30% come from families on public assistance, and because of Job Corps the majority embark upon a career leading to independent lives.
- Most have never held a full-time job, and because of Job Corps 75% secure employment or enter the military.
- On average, Job Corps enrollees read slightly before the 8th grade level, and because of Job Corps graduates improve their literacy levels by more than 2 grade levels.

For these compelling reasons, Mr. Chairman, I respectfully seek your consideration of the National Job Corps Association's (NJCA) fiscal year 2011 funding request of \$1.764 billion. This funding will ensure the continuation of Job Corps services to the very young people who are too often hit the hardest by socio-economic conditions beyond their control.

NJCA Fiscal Year 2011 Request

The NJCA requests a total of \$1.764 billion in the fiscal year 2011 budget: \$1.644 billion in operating expenses, \$110 million in capital expenses, and \$10 million in incremental expansion.

In these turbulent economic times when youth unemployment remains as high as 28 percent, it is essential to invest in successful programs that prepare young people with the skills they need to find jobs and lead productive lives. The \$1.764 billion fiscal year (FY) 2011 budget request for Job Corps would:

- Educate and train more than 60,000 out-of-school, out-of work youth.
- Create hundreds of new jobs for Job Corps special needs instructors, reading specialists, mentors and tutors at the 124 Job Corps centers located in all 50 states, the District of Columbia and Puerto Rico.
- Create 14.5 jobs directly and 9.5 local jobs indirectly for every million dollars a Job Corps center spends.
- Stimulate approximately \$2 of local activity for every \$1 spent by Job Corps.

In order to serve the growing numbers of unemployed and at-risk youth choosing Job Corps' unique and holistic residential services and support, the program requires additional funding to:

- 1) maintain student services at 124 Job Corps centers.
- 2) serve the growing number of students with special needs.
- 3) retain Job Corps students by enhancing the program's residential after school training.
- 4) optimize the use of Job Corps facilities for non-residential students.

Maintain Student Services at 124 Job Corps Centers

The NJCA's request includes a 2.5 percent increase in Job Corps' operations account to: (1) close the Office of Job Corps' operational shortfall estimated at \$40 million; allow the opening of the Ottumwa, Iowa Job Corps Center once construction is complete; (3) support the enhancement of student services; (4) cover the rising costs of goods and services, including heating fuels, prescription drugs, foods and transportation; (5) fund the Department of Labor/Office of Job Corps' initiative to transition the program to a standards-based system; and (6) address Job Corps' staff salary gap in order to reach parity with local public school teachers and instructors.

Serve the Growing Number of Students with Special Needs

The average Job Corps student reads below the 8th grade level upon enrollment, and it is estimated that 60 percent of Job Corps students have some type of learning disability. The NJCA's fiscal year 2011 budget request includes a \$10 million request to acquire full-time special needs instructors to conduct diagnostic testing on students presenting signs of a learning disability, develop individualized lesson plans and provide hands-on academic remediation. The \$10 million request also includes the ability for Job Corps centers to hire part-time reading specialists, as well as critical training tools to strengthen reading programs and to serve students with moderate to serious learning disabilities, including dyslexia, attention deficit and hyperactivity disorders and speech impediments.

Retain Job Corps Students by Enhancing the Program's Residential After School Training

As a residential program, Job Corps provides additional learning opportunities in the evening. Students work with volunteers, retired senior citizens and professional staff to practice job interview techniques, learn how to manage their personal finances, participate in healthy nutrition and physical fitness programs, and contribute to their local communities through community and service learning projects, all of which contributes to building a more well-rounded graduate and citizen. With an additional investment of \$5 million in fiscal year 2011, Job Corps could hire new instructors and obtain new equipment to enhance these critical after-hours programs.

Optimize the Use of Job Corps Facilities for Non-Residential Students

As I am sure you are aware, there is a growing number of youth who leave our high schools, whether with a diploma or not, who don't have the skills to begin a career. Job Corps' national infrastructure could lend itself well to serving the growing numbers of out-of-school, out-of-work youth in the evening in our empty classrooms. Through Congress' support and a modest investment in fiscal year 2011, Job Corps could pilot an evening health care training program for eligible, non-residential Job Corps students. Health care training would be an ideal for a pilot given the continued growth in the demand for health care workers. This evening program could include vocational offerings in clinical medical assistant, medical administration, dental assistants, optician, pharmacy technicians, home health aides, and licensed practical nurses.

Ensure the Safety of Students in Federal Facilities

Job Corps continues to struggle to repair, renovate and replace deteriorating structures and mechanical systems that threaten the health and safety of Job Corps students. The NJCA's fiscal year 2011 request includes \$110 million to address critical repairs and renovations at existing Job Corps facilities.

Provide Funding for Two New Job Corps Sites

Pursuant to language included in the final fiscal year 2010 Omnibus Appropriations conference agreement, directing the U.S. Department of Labor to announce the competition in 2010 for additional Job Corps sites in both rural and urban areas, the NJCA's fiscal year 2011 request includes funding required to acquire property, conduct environmental safeguards and prepare preliminary architecture and engineering studies. It is estimated that a newly built Job Corps facility generates an average of 430 jobs – 258 directly employed workers and 170 positions supported through additional local economic activity.

But, don't just take it from me that Job Corps works. I am joined here today by one of those students, a remarkable young man, Dionte Brooks. Dionte as a teenager assumed responsibilities that most of us only take on as adults, being forced by circumstance to provide for his family. He made some tough choices along the road, including dropping out of high school. However, Dionte enrolled at the Earle C. Clements Job Corps Center and is now becoming a role model to others.

**Testimony
before the U.S. House of Representatives
Subcommittee on Labor, Health and Human Services and
Education Appropriations**

**Dionte Brooks, Job Corps Student,
Earle C. Clements Job Corps Center
May 12, 2010**

Good morning. My name is Dionte Brooks. First of all, I would like to say thank you for your very valuable time. I also want to say thank you to the Committee for the money that pays for Job Corps. I am here to tell you how Job Corps has impacted my life.

I am the oldest of two with a loving, dedicated and tough single mother standing behind us. But, she didn't have it easy. I grew up on the streets of Oakland, California – gangs, drugs, drive bys, funerals – those were the things I witnessed every day. It just came with the territory.

My mom desperately wanted to change our circumstances, but nothing was easy. She raised two boys in one of the toughest areas with little to no support. She held down a full-time job while attempting to earn a degree in counseling. She was only 22 at the time. Yet, for all of her hard work it seemed as if only bad fortune came her way. She really needed help.

Growing up, I felt I had few options. I was the oldest. I felt obligated to help my mom in any way possible. So, I decided to turn to the streets and to a gang. While living on the streets, I did what I was asked to do so that I could provide for my family. That was how I lived.

When mom came home one day saying we were moving to Florida, I remember thinking "here's my chance for something better." I enrolled in Dillard High School, a performing arts school, where I was introduced to the saxophone. I couldn't read music, but could listen to what was being played and play it back. I was finally in place where there were resources available to assist me in becoming successful and learning something I cared about. Unfortunately, I was forced to focus on helping my family, not on school. We continued to struggle to live each and every day. So, I dropped out of high school.

My mother always told me that school came first but, it was only after seeing my mother struggle even with her credentials and work experience that I started to realize how hard it would be without all of those things myself. When, through her determination, she started to get her life back on track, I saw that education and hard work really paid off. I knew I had to do something with my life.

My mom had some experience with Workforce One, a workforce development agency, and its relationship with Job Corps. She told me to go sign up for Job Corps so that I could complete my education and earn a certification that would help me get a job.

All of my life I've heard people say that they made it "in spite of" this or that. I feel very few people, if any, make it "in spite of" something. Most make it "because of" something. I made it because of Job Corps. I made it because of the Job Corps staff who trained, counseled, mentored, pushed, and sometimes punished me during my stay. Because of them, I learned the skills to succeed.

Today, because of Job Corps, I am finishing up my high school diploma. I have taken advantage of all the opportunities Job Corps throws my way. I have completed the electrician trade, learned the importance of giving back through community service activities, served as a student ambassador and on the Student Government Association and participated in the Earle C. Clements Job Corps jazz band as the lead instrumentalist.

Because of Job Corps, I stand before you as a confident young man who can't wait to see what lies ahead. Thanks to Mr. Cooper, I may have the opportunity to audition for a spot studying music at Western Kentucky State. I want to improve my skills as an alto saxophonist, earn a college degree and prove I can do something "because of" the belief Job Corps had in me. Job Corps has helped me change my life. I have become a better man and can now do for others as well as myself.

Brigadier General (Retired) Billy R. Cooper

Brigadier General Billy Cooper holds a Bachelor of Science degree in Education Administration from Cameron University, Lawton, Oklahoma, and a Master's degree in Education Administration from Georgia State University, Atlanta, Georgia. He is a Dallas, Texas native.

He was commissioned a second lieutenant on graduation from Officer Candidate School in December 1968. In 1969, he was assigned as Forward Observer and later Executive Officer, Battery A, 1st Battalion, 21st, 1st Cavalry Division in Vietnam.

Some other assignments include Artillery Tactics Instructor, Commander, Battery C, 1st Battalion, 22d Artillery, 1st Armored Division in Germany. He completed the Field Artillery Officer Advanced Course, Fort Sill, and later served as Assistant Professor of Military Science, Albany State College, Albany, Georgia. He later served as Field Artillery Staff Officer at the Field Artillery School and Operations Officer, 214th Field Artillery, Fort Sill. As a Lieutenant Colonel he Commanded, 2d Battalion, 1st Field Artillery, 1st Armored Division, Germany.

After graduation from the National War College, he became a Senior Operations Officer and later Assistant Deputy Director of Operations, on the Joint Staff in the Pentagon, Washington, DC. Returning to Fort Sill, he served as the Training and Doctrine Command System Manager for Fire Support Command, Control and Communications Systems and later commanded the 214th Field Artillery Brigade, 3rd Corps Artillery. After a second tour in the Pentagon as Chief, Fire Support Division and Assistant Director of Requirements, Office of the Deputy Chief of Staff for Operations – Force Development, he was promoted to brigadier general on November 1, 1996. He became Joint Rear Area Coordinator, US Central Command, MacDrill Air Force Base, Tampa, Florida, in March 1997 with duty in the Persian Gulf and the Horn of Africa.

General Cooper retired from active Army service in August 2001. His awards and decorations include: Defense Superior Service Medal, Legion of Merit with one Oak Leaf Cluster, Bronze Star Medal, Defense Meritorious Service Medal, Meritorious Service Medal with three Oak Leaf Clusters, Joint Chiefs of Staff Identification Badge, and the Army Staff Identification Badge.

Immediately following retirement General Cooper assumed duties as Director of the Cleveland Job Corps Center with Applied Technology Systems Incorporated (ATSI). He held this position for twenty months.

He currently serves as Center Director, Earle C. Clements Job Corps Academy, with Management Training Corporation.

Brigadier General Cooper is married to the former Dorothy Bayson. They have two daughters, Charlyn and Karen, and one granddaughter, Adrianna.

Mr. OBEY. You too. Thank you much.
Next, Joseph Sharpe from the American Legion.

WEDNESDAY, MAY 12, 2010.

VETS PROGRAMS

WITNESS

JOSEPH C. SHARPE, JR., DIRECTOR, NATIONAL ECONOMIC COMMISSION, AMERICAN LEGION, DEPARTMENT OF LABOR

Mr. SHARPE. Mr. Chairman and members of the Subcommittee, the American Legion thanks you for this opportunity to present its views on fiscal year 2011 funding issues under your jurisdiction. The Department of Labor's Veterans' Employment and Training Service administers the following programs: Disabled Veterans' Outreach Program, the Local Veterans' Employment Representatives State grant programs; Transition Assistance Programs; Veterans' Preference and Uniformed Services Employment and Reemployment Rights Act, USERRA; Homeless Veterans' Reintegration Program; Veterans Workforce Investment Program; and the National Veterans' Training Institute. VETS plays a vital role in promoting the economic security of America's veterans by assisting them in finding meaningful employment.

The American Legion believes staffing levels for DVOPs and LVERs should match the needs of the veteran's community in each State and should not be based solely on the fiscal needs of the State government. Such services will continue to be crucial as today's active duty service members, especially those returning from Iraq and Afghanistan, transition into the civilian workforce. Adequate funding will allow the programs to increase staffing to provide comprehensive case management job assistance to disabled and other eligible veterans.

The American Legion recommends \$267 million to the Department of Labor's VETS State Administration Grants for fiscal year 2011. And please note that the amount recommended for State grants include funds for the Transition Assistance Program.

The American Legion also recommends \$50 million for the Homeless Veterans Reintegration Program in fiscal year 2011. The program has successfully integrated homeless veterans into meaningful employment at a high percentage. In addition, the HVRP is the only nationwide program focused on assisting homeless veterans to reintegrate into the workforce.

The American Legion also recommends \$6 million for the National Veterans' Employment and Training Service Institute in fiscal year 2011 so that VETS staff can receive comprehensive training that will ultimately turn into higher levels of proficiency for them and more employment opportunity for veterans and their families.

The American Legion recommends \$20 million for the Veterans Workforce Investment Program, VWIP, in fiscal year 2011. The increase in funding for VWIP would ensure continued efforts in life-long learning and skills development programs that are designed to serve the most at-risk veterans, those with service-connected disabilities and those who recently separated.

The American Legion recommends \$61 million for the Program Management that encompasses Uniformed Services Employment and Reemployment Rights Acts, USERRA, and Veterans' Employment Opportunity Act, VEOA, in fiscal year 2011, to ensure service members who are deployed return to their jobs and Federal agencies are properly adhering to veterans' preference rights.

Finally, the American Legion is requesting a total of \$404 million for the Department of Labor's Votes Program.

In conclusion, thank you for the opportunity to submit the American Legion's recommendations on funding for the VETS program in the Department of Labor.

[Written statement by Joseph C. Sharpe, Jr., follows:]

**STATEMENT OF
JOSEPH C. SHARPE, JR., DIRECTOR
NATIONAL ECONOMIC COMMISSION
THE AMERICAN LEGION
BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES
ON
FY 2011 BUDGET PRIORITIES**

MAY 12, 2010

Mr. Chairman and Members of the Subcommittee, The American Legion thanks you for this opportunity to present its views on Fiscal Year (FY) 2011 funding issues under your jurisdiction.

**DEPARTMENT OF LABOR VETERANS EMPLOYMENT AND TRAINING SERVICE
(DOL-VETS)**

The Department of Labor's Veterans' Employment and Training Service (VETS) offers employment and training services to eligible veterans through a non-competitive Jobs for Veterans State Grants Program.

VETS administers the Disabled Veterans' Outreach Program (DVOP) and Local Veterans' Employment Representatives (LVER) state grant programs; Transition Assistance Program; veterans' preference and Uniformed Services Employment and Reemployment Rights Act (USERRA); Homeless Veterans' Reintegration Program (HVRP); Veterans Workforce Investment Program (VWIP); and the National Veterans' Training Institute (NVTI). VETS' mission is to promote the economic security of America's veterans by assisting them in finding meaningful employment.

VETS should remain a national program with federal oversight and accountability. The American Legion is eager to see this program grow; and especially would like to see greater expansion of entrepreneurial-based, self-employment opportunity training. The mission of VETS is to promote the economic security of America's veterans.

The American Legion believes staffing levels for DVOPs and LVERs should match the needs of the veteran's community in each state and should not be based solely on the fiscal needs of the state government. Such services will continue to be crucial as today's active duty service members, especially those returning from Iraq and Afghanistan, transition into the civilian work world. Adequate funding will allow the programs to increase staffing to provide comprehensive case management job assistance to disabled and other eligible veterans.

**MAKE TRANSITIONAL ASSISTANCE PROGRAM (TAP)/DISABLED
TRANSITIONAL ASSISTANCE PROGRAM (DTAP) MANDATORY**

The American Legion is deeply concerned with the timely manner in which veterans, especially returning wartime veterans, transition into the civilian sector.

DOD estimates that 79 percent of separating active-duty service members attend the full TAP seminars but only 35 percent of Reserve Components service members attend. The American Legion believes these attendance numbers are a disservice to all transitioning service members, especially Reserve Component service members.

The American Legion strongly believes all service members would benefit greatly by having access to the resources and knowledge that TAP/DTAP provide. TAP/DTAP also needs to update their programs to recognize the large number of National Guard and Reserve business owners who now require training, information and assistance while they attempt to salvage or recover a business which they abandoned to serve their country.

The American Legion strongly recommends DOD require all separating, service members, including those from Reserve Component units, participate in Transition Assistance Program and Disabled Transition Assistance Program training not more than 180 days prior to their separation or retirement from the Armed Forces.

The American Legion recommends \$267 million to DOL-VETS State Administration Grants for FY 2011 (Note: Amount recommended for State Grants include funds for the Transition Assistance Program).

HOMELESSNESS (DOL-VETS)

The American Legion notes there are approximately 107,000 homeless veterans on the street each night. This number, compounded with approximately 200,000 service members entering the civilian sector each year since 2001 with at least a third of them potentially suffering from mental illness, indicates that programs to prevent and assist homeless veterans are needed.

The Homeless Veterans Reintegration Program (HVRP) is a competitive grant program. Grants are awarded to states or other public entities and non-profit organizations, including faith-based organizations, to operate employment programs that reach out to homeless veterans and help them become gainfully employed. HVRP provides services to assist in reintegrating homeless veterans into meaningful employment in the labor force and stimulates the development of effective service delivery systems that will address the complex problems facing veterans. HVRP is the only nationwide program focused on assisting homeless veterans to reintegrate into the workforce.

The American Legion recommends \$50 million for this highly successful grant program in FY 2011.

TRAINING

The National Veterans' Employment and Training Services Institute (NVTI) was established to ensure a high level of proficiency and training for staff that provide veterans employment services. NVTI provides training to federal and state government employment service providers in competency-based training courses.

The American Legion recommends \$6 million for NVTI in FY 2011.

VETERANS WORKFORCE INVESTMENT PROGRAM (VWIP)

VWIP grants support efforts to ensure veterans' lifelong learning and skills development in programs designed to serve most-at-risk veterans, especially those with service-connected disabilities, those with significant barriers to employment, and recently separated veterans. The goal is to provide an effective mix of interventions, including training, retraining, and support services, that lead to long term, higher wage and career jobs.

Veterans need proper training and tools to begin new careers after they leave military service. The Veterans Workforce Investment Program (VWIP) has received \$9.6 million in funding, which allows the program to operate in only 15 states. The problem is clearly a lack of adequate funding. Veterans are the only participants in this program. The budget baseline needs to be increased to allow VETS to train eligible veterans in all 50 states in FY 2011.

The American Legion recommends \$20 million for VWIP in FY 2011.

EMPLOYMENT RIGHTS AND VETERANS' PREFERENCE

The Uniformed Services Employment and Reemployment Rights Act (USERRA) protects civilian job rights and benefits of veterans and members of the armed forces, including National Guard and Reserve service members. USERRA prohibits employer discrimination due to military obligations and provides reemployment rights to returning service members.

Veterans' Preference is authorized by the Veterans' Preference Act of 1944. The Veterans' Employment Opportunity Act (VEOA) of 1998 extended certain rights and remedies to recently separated veterans. VETS have the responsibility to investigate complaints filed by veterans who believe their Veterans' Preference rights have been violated and to conduct an extensive compliance assistance program.

Veterans Preference is being unlawfully ignored by numerous agencies. Whereas figures indicate a decline in claims by veterans of the current conflicts compared to Gulf War I, the reality is that employment opportunities are not being properly publicized. Federal agencies, as well as federal government contractors and subcontractors, are required by law to notify the Office of Personnel Management (OPM) of job opportunities, but more often than not these job opportunities are never made available to the public. The VETS program investigates these claims and corrects unlawful practices.

The American Legion recommends \$61 million for Program Management that encompasses USERRA and VEOA in FY 2011.

In conclusion, thank you for the opportunity to submit The American Legion's recommendations on the funding of DOL-VETS.

**JOSEPH C. SHARPE JR.
DIRECTOR
NATIONAL ECONOMIC COMMISSION
THE AMERICAN LEGION**

Joseph C. Sharpe Jr. was appointed to the position of Director of the Economic Commission in April 2009. Prior to serving as Director, he served as Deputy Director of the Economic Commission, Health Care Field Representative and Assistant Director of the Veterans Affairs and Rehabilitation Commission.

He is a graduate of The Johns Hopkins School of Advanced International Studies in Washington, DC, where he earned a M.A. in International Relations and Economics. He also has two Graduate Certificates in International Business and Trade and Health Care Management from Georgetown University. Joseph also earned his B.A. in Sociology from the University of Maryland, College Park, MD. He is currently enrolled in a part time MBA program with Johns Hopkins University.

In 1982, he entered the United States Army. After completing initial training at Ft. Sill, OK, and Ft. Sam Houston, TX, he served as a Drug and Alcohol Counselor with the 2nd Infantry Division in South Korea. He also served as a Mental Health Counselor in Ft. Benning, GA, worked as a Behavioral Science Research Specialist at the Walter Reed Institute of Research, Heidelberg, Germany, and was appointed as the Non Commissioned Officer in Charge of Inpatient Social Work and Psychiatry Service, Walter Reed Army Medical Center, in Washington, DC. In addition to his active duty service, Joseph is currently serving with the 354th Civil Affairs Brigade, U.S. Army Reserve, Riverdale, MD, as the Non Commissioned Officer in Charge of the Brigades Economics and Commerce Team.

During his military service with the Army Reserve Sergeant First Class Sharpe was deployed twice overseas, in Operation Joint Forge, Bosnia-Herzegovina, and recently for the Global War on Terrorism, in which he received the Bronze Star Medal for work completed in the restoration and improvement of public and private financial institutions and banking services in Iraq.

Originally from Chicago, Illinois, he and his family currently reside in Bristow, Virginia.

Mr. OBEY. Thank you for your testimony and for staying within the time limit. I appreciate it.

Next, Robert Pleasure, from the Building and Construction Trades Department. How are you?

WEDNESDAY, MAY 12, 2010.

**NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY
AND HEALTH**

WITNESS

ROBERT PLEASURE, SPECIAL ASSISTANT TO THE PRESIDENT, BUILDING AND CONSTRUCTION TRADES DEPARTMENT, AFL-CIO

Mr. PLEASURE. Good morning, Mr. Chairman, members of the Committee. As the Chairman just indicated, my name is Robert Pleasure. I am Assistant to the President of the Building and Construction Trades Department at AFL-CIO. The purpose of our testimony today is to request your support for increased funding for the National Institute for Occupational Safety and Health, NIOSH, and its Construction Research Program.

Despite some improvements in workplace safety and health as a result of research and efforts of the Occupational Safety and Health Administration, still, nearly 15 American workers die each day from workplace injuries, and another 134 die from work-related diseases.

Four out of those 15 that die on the job are employed in the construction industry. Indeed, the construction industry has the unfortunate distinction of being the single most hazardous industry from the perspective of the number of fatalities in the United States, accounting for some 1,200 construction workers killed on the job each year.

While construction workers make up only 8 percent of the U.S. workforce, they account for more than 22 percent of all work-related deaths. In fact, due to exposures to an array of toxic and hazardous substances, construction workers have unacceptably high levels of occupational disease, including cancer, silicosis, asbestosis, and other heart, lung, and neurological diseases.

I have to say that I also have had the dubious distinction of having worked on construction safety and health for a number of years as Director, in the past, of CPWR, the National Construction Center that has been supported over the years by NIOSH. But that program has been at \$5 million for many, many years, from the early 1990s until the present, and I do not discount the important hazards that other workers are exposed to, having spent time, in my work life, with the Federal Mine Safety and Health Review Commission.

I know that there are many other industries that face these challenges, but construction not only faces these very high rates of injury and illness, but we know now, as we move from research to practice, how to abate these hazards; and the research we are now focused on and leading a vanguard effort by NIOSH is this R2P, research to practice, program.

So I speak as any person that might represent the mine workers, for example, or offshore workers, many of whom are part of the

construction industry, with a sense of urgency. This is not just a question of research, but it is a movement from surveillance to intervention, from research to practice.

Except for a special \$80 million for the World Trade Center Health Program and some \$7 million for nanotechnology research, the President's fiscal year 2011 NIOSH budget request remains at last year's level; and, as I said, the Construction Research Center has remained at the same level going back to the mid-1990s.

While we support both the WTC program and the nanotechnology program, we believe that a major increase in the NORA budget, the National Occupational Research Agenda budget, for NIOSH is essential.

With respect to that funding, we recommend a \$25 million increase over the President's \$124 million NORA request, which was a static request. And we ask particularly for support for the work that is done in the construction industry.

I thank you very much for this opportunity to appear before you. We brought our data up to 2008 BLS data in what I submitted today, the 35 copies, and I ask your permission to include those changes in the record.

Mr. OBEY. Sure. All right.

Mr. PLEASURE. Thank you very much.

[Written statement by Robert J. Pleasure follows:]

Name: Robert J. Pleasure

Title: Special Assistant to the President, Building and Construction Trades Department, AFL-CIO

Representing: The Building & Construction Trades Department, AFL-CIO
Washington DC.

Testimony before the House Appropriation Subcommittee on Labor-HHS-Education on the FY 2011 budget for the Department of Health and Human Services; National Institute for Occupational Safety & Health

Hearing Date & Time: May 12, 2010, 2:30 PM

Summary: The purpose of this testimony is to request from the House Appropriations Subcommittee on Labor-HHS-Education support for increased funding for the National Institute for Occupational Safety & Health (NIOSH), and its construction research program.

Mr. Chairman, members of the Committee. My name is **Robert J. Pleasure** and I am the Special Assistant to The President of the Building and Construction Trades Dept. AFL-CIO (BCTD).

The purpose of this testimony is to request your support for increased funding for the National Institute for Occupational Safety & Health (NIOSH), and its construction research program,

Despite some improvements in workplace safety and health, nearly 15 American workers die each day from workplace injuries, and another 134 die from work-related diseases. Four out of those 15 killed every day are employed in the construction industry.

Indeed, construction has the dubious distinction of being the single most hazardous industry in the United States accounting for some 1,200 construction workers killed on the job each year. While construction workers make up only 8 percent of the U.S. workforce, they account for more than 22 percent of all work-related deaths.

Moreover, due to exposures to an array of toxic and hazardous substances, construction workers have unacceptably high levels of occupational disease including cancers, silicosis, asbestosis, and other heart, lung and neurological diseases.

In addition to the human tragedy, the economic costs are staggering. The total cost of fatal and nonfatal injuries and disease in the construction industry has been estimated at nearly \$13 billion annually. And, that does not count the costs of workers' compensation, which, at \$30 billion a year, are twice that of manufacturing and three times that for all industries.

NIOSH is the only federal agency responsible for conducting research and making recommendations for the prevention of work-related injury and illness. Yet it is one of the most under funded health research agencies in the federal government, and is hamstrung by being buried in the bowels of the Center for Disease Control (CDC) bureaucracy where it remains an orphan.

Except for a special \$80 million increase for the World Trade Center (WTC) health program and some \$7 million for nanotechnology research, the President's FY 2011 NIOSH budget request remains at last year's level.

While we support both the WTC and nanotechnology programs, we think it's high time for the Congress to review the entire NIOSH program with an eye towards dramatically improving both its structural place within the Department of HHS and its funding.

With respect to funding, especially funding for the NIOSH National Occupational Research Agenda (NORA) program, we recommend a \$25 million increase over the president's static \$124.5 million NORA request.

We particularly ask your consideration of expanded NORA funding for the "construction

initiative” that seeks to (1) identify safety and health problem areas and obstacles to prevention and (2) translate that research into practice via partnerships and field studies across a variety of construction trades.

A recent National Academy of Sciences’ Institute of Medicine review of the NIOSH construction program, recommended:

- Increased funding for the program.
- Strengthening NIOSH's internal management of the program.
- Retaining “The National Construction Center” as the main focus for “research to practice” (R2P) activities.

Between 1997 and 2007, funding for the Construction Research Program averaged about \$17.8 million annually. The NAS report concluded that *the committee finds the funding level inadequate and recommends that high-level attention be given to determining how to provide program resources that are commensurate with a more robust pursuit of the program’s goals...*

Given the research agenda outlined and recommended by the NAS Review Committee, we believe that the construction program should be placed on a sounder financial footing and recommend that it receive additional funds from the NIOSH/NORA budget increase we have requested.

To address the many construction safety and problems in our industry, the BCTD research arm – The Center for Construction Research and Training (CPWR)-- has, for many years, been working with NIOSH through the NORA construction research initiative. The CPWR was recently awarded another 5-year extension of its NIOSH contract to serve as the “National Construction Center” to coordinate the “Research to Practice” program.

We strongly believe that the best way to address what has become a safety & health crisis in our industry is through targeted and applied research to better understand the causes of construction-related incidents and illness and to find ways to implement solutions on construction sites.

While there is certainly an additional need for better standards and enforcement by the Department of Labor, NIOSH construction research is the critical first step towards a safer and healthier construction workforce.

As you consider the FY 2011 Labor-HHS-Education appropriation bill, we urge you to take some time to consider the safety & health of our building and construction workforce. The current situation is simply unacceptable and, in light of demands for increased public spending for construction projects to stimulate the economy, the safety & health pressures on our workers will only become more intense.

Thank you.

Fatalities in the U.S. Construction Industry

| | 2003 | 2004 | 2005 | 2006 | 2007 |
|----------------|-------|-------|------|------|------|
| Construction | 1171 | 1278 | 1243 | 1297 | 1239 |
| Transportation | >800 | >800+ | >800 | <900 | <900 |
| Manufacturing | >400 | >400 | <400 | >400 | 400 |
| Agriculture | >700 | >600 | >700 | >600 | 600 |
| Mining | >100+ | >100 | >100 | 200 | <200 |

Source: Center for Construction Research and Training

Safety & Health Facts*

- The construction industry employs only 8% of the workforce but it suffers **22% of all work-related deaths**.
- Low-skilled, low-paid workers suffer the most fatalities.
- Construction establishments with less than 20 workers account for 55% of all fatalities.
- **Lung cancer deaths are 50% higher** among construction workers than the U.S. population, adjusted for smoking.
- Construction workers are **two times more likely than the general population to have chronic obstructive lung diseases**.
- Construction workers are **five times more likely than the general population to have a cancer** of the lung lining (mesothelioma) and 33 times as likely to have asbestosis, an incurable and fatal lung disease.
- 30-40% of construction workers suffer musculoskeletal disorders and **chronic pain**.
- 50% of construction workers have noise-induced **hearing loss**.
- Construction workers account for 17% of workers with elevated blood lead levels/
- Welding fumes are responsible for 75% of boilermakers, 15% of ironworkers and 7% of pipefitters exceeding the accepted 8-hour level for manganese exposure; a known neurotoxin.

* Source: **Construction Chart Book**, Center for Construction Research and Training (2007)

Building and Construction Trades (202) 347-1461
 Department, AFL-CIO Rpleasure@bctd.org
 815 16th Street NW
 Washington, DC 20006

Robert J. Pleasure

- Current Occupation** Special Assistant to the President, Building and Construction Trades Department, AFL-CIO. Served on Obama-Biden Transition Team, U. S. Department of Energy, during transition and with un-paid leave from Building and Construction Trades Department.
- Experience**
- Director of Education, Building and Construction Trades Department, AFL-CIO, 2004-2009.
 - Executive Director, AFL-CIO Center for Working Capital, 2001-2004.
 - Executive Director, CPWR, the research arm of the Building and Construction Trades Department, 1998-2001.
 - Assistant to the President of the AFL-CIO for Education and Training, 1996-1998.
 - Executive Director, George Meany Center for Labor Studies, National Labor College, 1985-1996.
 - Associate General Counsel (1978-1994) and Assistant General Counsel (1972-1978), United Brotherhood of Carpenters and Joiners of America.
 - General Counsel, Federal Mine Safety and Health Review Commission, 1978.
 - Associate, District of Columbia and Detroit Law Firm, Zwerdling, Maurer, and Diggs, 1971-1972, and Assistant General Counsel, American Federation of State, County and Municipal Employees, AFL-CIO, 1970-1971.
 - Attorney-Advisor, National Labor Relations Board Member Gerald A. Brown, 1969-1970.
 - Assistant to the Chairman, New York City Office of Collective Bargaining, 1968-1969.
- Education**
- J.D. University of Michigan School of Law, 1967.
 M. Sc. London School of Economics, 1967.
 B. A. Honors, University of Pennsylvania, 1964.
- Professional Qualifications**
- Admitted to bar as attorney in the District of Columbia. Admitted to practice before several Federal Circuit Courts of Appeal and the Supreme Court of the United States.
- Academic Affiliations**
- Currently Adjunct Professor, University of Baltimore, Yale Gordon Graduate School, teaching Employment Law and Contracts U. Baltimore Legal and Ethical Studies. Former member of advisory committee to the National Occupational Research Agenda, NIOSH; Formerly, Member of the Technical Electronic Product Radiation Safety Standards Committee, Center for Devices and Radiological Health, U. S. Food and Drug Administration; Former Member of the National Board of Directors, Industrial Relations Research Association; Former Commissioner, American Council of Education, Commission on Non-Collegiate Credit and Credentials; former Chairman, Council on Labor Law and Labor Relations, Federal Bar Association.

Mr. OBEY. Thank you much.
Next, James Kohlmoos from Knowledge Alliance.

WEDNESDAY, MAY 12, 2010.

K-12 ED

WITNESS

JAMES W. KOHLMOOS, PRESIDENT, KNOWLEDGE ALLIANCE, DEPARTMENT OF ENERGY

Mr. KOHLMOOS. My name is Jim Kohlmoos, this is Augustus Mays, and we are both from Knowledge Alliance, which is a coalition of 35 education organizations dedicated to promoting the expanded use of research-based knowledge in policy and practice. We greatly appreciate this opportunity to testify.

And to you, Mr. Chairman, thank you so much for your skilled and dedicated leadership on so many critical issues of equity and excellence in education over so many years. We will greatly miss you, but your legacy will endure for a very, very long time. So thank you, sir.

Mr. OBEY. Thank you.

Mr. KOHLMOOS. We wish to offer three critical ideas as you grapple with this appropriations bill.

Number one, the Nation is still at risk. If you were to read the Nations At Risk Report this afternoon, you would think that it was written just yesterday, not in 1983. The critical issues that we face today were pervasive more than 25, 30 years ago: the trend towards mediocrity, glaring achievement gaps, diminishing global competitiveness.

Even though education reform has been a top priority for the last 30 years, why have we made so little progress? A lack of political will? A fractured education system? The curriculum? Human capital? We think it is all of the above and more. And the more in this case is that we do not have in place an education and R&D infrastructure that can deliver the kind of research-based solutions in ways similar to other sectors like medicine, agriculture, energy, and defense. Education is not yet an evidence-based, knowledge-driven field.

Second, education funding in R&D ranks near the bottom. While there are a number of structural flaws in the education's R&D infrastructure, the root cause is the woefully meager Federal investment. Consider this: \$78; \$0.38. The difference between what you can buy with \$78 versus \$0.38 is obviously very significant. In similar proportions, it is the difference between the Federal investment in defense R&D, at \$78 billion, and the Federal investment in education R&D, at just \$170 million. For a \$500 billion industry like K-12 education to invest less than one-one hundredth of a percent in R&D is a recipe for perpetual failure.

Third, invest more in what is currently working. Despite the low investment in education R&D, there is reason for optimism in the pockets of excellence in the knowledge sector in education that can invigorate the R&D enterprise. Specifically, I am referring to three existing programs that lay a strong foundation from which to grow in the future: the Comprehensive Assistance Center Programs for

providing technical assistance to States; the Regional Education Laboratories that serve as an essential bridge between the research community and State and local agencies; and National R&D Centers for conducting research on issues of enduring national significance.

As outlined in my written comments, we urge substantial increases in these three vital programs. And when combined with the resources for school improvement and innovation in the ARRA funds, these three programs can create a powerful launchpad from which to erect a world-class R&D system for education.

Mr. Chairman, members of the Committee, the time has arrived to unleash America's ingenuity, to solve our most pressing education problems, to deliver break-the-mold solutions to our schools, and to guide a new knowledge and innovation revolution in teaching and learning. You can begin doing that by taking on our recommendations for increased investment in Federal R&D.

Thank you so much.

[Written statement by James W. Kohlmoos follows:]



One St Matthews Court Washington DC 20036 (202) 518-0847 www.KnowledgeAll.net

**Testimony submitted by
James W. Kohlmoos, President, Knowledge Alliance**

**To
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies, Committee on Appropriations United States
House of Representatives**

**Regarding
FY 2011 appropriations for the U.S. Department of Education**

May 12, 2010

Summary

Since the release of the Nation at Risk report more than 25 years ago, educational improvement has been a top priority for U.S. policymakers, educational leaders, entrepreneurs, foundations, and practitioners. Yet the pace of improvement in school districts has been incremental at best, and by many measures, educational outcomes in the United States have slipped in comparison with other countries.¹

In fields such as medicine, defense, agriculture, and technology, large and vibrant research, development, and dissemination (RD&D) infrastructures serve as the leading catalysts for problem solving and innovation. In education, however, the RD&D enterprise is neither of the size nor scope to sustain and scale the kind of innovative, transformational change needed by our school systems to address current and future learning needs. As a result, education reform efforts at the local, state and national levels suffer from a pervasive capacity crisis where the urgent need for research-based solutions to critical educational problems far surpasses the supply of useable knowledge and relevant expertise.

Knowledge Alliance recommends significantly increasing investments in education's RD&D infrastructure and the development and implementation of innovative research-based solutions. Our recommended investments in six interrelated programs at the US Department of Education will help develop a robust capacity at the state and local levels to solve education's most persistent problems of practice and policy.

With America's future competitiveness at stake, the time has come to unleash America's ingenuity to solve our most pressing education problems, deliver break-the-mold solutions to our schools, and guide a new knowledge and innovation revolution in teaching and learning.

¹ OECD, *PISA 2006: Science Competencies for Tomorrow's World* (Paris: 2007).

Testimony

On behalf of Knowledge Alliance, I am pleased to submit this testimony to the subcommittee regarding our recommendations for the FY 2011 Labor, Health and Human Services and Education appropriations bill as they relate to the US Department of Education.

Knowledge Alliance is a non-profit, non-partisan coalition dedicated to the effective use of research-based knowledge in shaping policy and practice in K-12 education. We are a strong and dynamic community of successful education organizations and agencies, all of which are constantly looking for new and better ways to support high-quality education research, development, dissemination, technical assistance and evaluation at all levels. We believe that the effective creation, translation and application of research-based knowledge can significantly accelerate and bring to scale nationwide efforts to improve academic performance and close achievement gaps for all students.

Critical Challenges

A nation still at risk --- Since the release of the Nation at Risk report more than 25 years ago, educational improvement has been a top priority for U.S. policymakers, educational leaders, entrepreneurs, foundations, and practitioners. Yet the pace of improvement in school districts has been incremental at best, and by many measures, educational outcomes in the United States have slipped in comparison with other countries.

In fields such as medicine, defense, agriculture, and technology, large and vibrant research, development, and dissemination (RD&D) infrastructures serve as the leading catalysts for problem solving and innovation. In education, however, the RD&D enterprise is neither of the size nor scope to sustain and scale the kind of innovative, improvements needed by our school systems to address current and future learning needs. As a result, education reform efforts at the local, state and national levels suffer from a pervasive capacity crisis where the urgent need for research-based solutions to critical educational problems far surpasses the supply of useable knowledge and relevant expertise.

Seriously deficient investments in education research and development – The Elementary and Secondary Education Act (ESEA) promotes the use of instructional practices and innovations supported by research, but the Department of Education spends less than one percent of its budget on research, development and statistics, one of the smallest of any cabinet level agency. (*American Association for the Advancement of Science*)

| Federal department/agency | FY 2011 research and development request (in millions of dollars) |
|---------------------------|---|
| Defense | 78,048 |
| Health and Human Services | 32,152 |
| NASA | 10,986 |

| | |
|--|------------|
| <u>Energy</u> | 11,219 |
| <u>National Science Foundation</u> | 5,547 |
| <u>Agriculture</u> | 2,448 |
| <u>Commerce</u> | 1,716 |
| <u>Veterans Affairs</u> | 1,180 |
| <u>Homeland Security</u> | 1,046 |
| <u>Transportation</u> | 901 |
| <u>Interior</u> | 772 |
| <u>Environmental Protection Agency</u> | 606 |
| <u>Education</u> | 383 |

This low level of investment means that education is ill equipped to rapidly develop, deliver and scale innovations as is done in other sectors through R&D. The bottom line is that schools and students will suffer without an increased investment in developing and testing research-based practices.

Rapidly expanding capacity crisis –According to a recent Center on Education Policy report, about one-third of U.S. public schools did not make Adequate Yearly Progress (AYP) in 2008-2009. In nine states and the District of Columbia, at least half the public schools did not make AYP and in a majority of the states (35 including D.C.), at least one-fourth of the schools did not make AYP. States and districts currently lack the sufficient resources, staff and expertise to address the growing demand to support low performing schools. This capacity crisis only exacerbates the complex challenges of transforming low performing schools and preparing all schools for the next generation of learning.

Urgent need for solutions -- Federal education policy has evolved in phases over the past 15 years. The focus on standards and assessments in the late 1980s and early 1990s spawned major attention on the alignment of standards, curriculum and assessments in the 1990s, which played a role in the current emphasis on accountability. The next logical step in this standards-based continuum is a more comprehensive and vigorous focus on solutions by providing significant new resources and expertise for turning around low performing schools and building the capacity for sustained improvement.

Recommendations

Our appropriations proposal for FY 2011 calls for greater federal investments in research-based programs to help states and districts respond to the rapidly increasing needs. We urge a stronger and more comprehensive federal effort to respond both to the greater demand for knowledge-based solutions and to the under-funded supply of well-tested practices and programs.

Top priority: A Knowledge, Innovation and Improvement Package

We urge you to consider six essential and interrelated programs as a knowledge-innovation- improvement package:

Comprehensive Centers *\$67.3M (\$10 M increase over President's request)* Our recommendation includes an increase of \$500 thousand, or 20%, of additional funding for each Comprehensive Center which would: 1) enable the 16 regional centers to expand their capacity building work with SEAs in such areas as resource allocation, data use, teacher effectiveness and school improvement; 2) support the five content centers' school improvement efforts in providing in-depth, specialized support in five key areas (assessment and accountability, instruction, teacher quality, innovation and improvement and high schools); 3) help states sustain their one-time ARRA school improvement efforts.

Regional Educational Laboratories *\$80.6M (\$10M increase over President's request)* Our proposed increase would: 1) expand a special triage "urgent response" system to address the most pressing, immediate educational reform issues in each region; 2) focus more attention on development and dissemination initiatives; 3) further support the crucial initiatives that are being implemented via the ARRA.

Research, Development & Dissemination *\$261M (same as the President's request)* Our recommendation would allow funding 1) for more rigorous research projects under existing programs in areas where the knowledge of learning and instruction is inadequate; 2) for new grants to support impact evaluations at the State and district level of the ARRA.

School Turnaround Grants *\$900M (same as the President's request)* The \$354.4 million increase requested for the School Turnaround Grants (currently School Improvement Grants) would help build State and local capacity to identify and implement effective interventions to turn around their lowest-performing schools. The proposed increase would create a sustainable base for long-term school improvement efforts.

Investing in Innovation Fund *\$500M (same as the President's request)* Our proposal would support a newly authorized ESEA program, modeled after the Investing in Innovation program in the ARRA and provide a substantial federal investment for scaling and sustaining evidence-based innovations. The proposal is a bold step in the right direction in building from and on a knowledge base for reform.

Race to the Top *\$1.35B (same as the President's request)* The request would support a newly authorized ESEA program, modeled after the Race to the Top program in the ARRA. The program would create incentives for comprehensive State and local reforms for improving student achievement and close the achievement gaps. The program would also encourage the broad identification, dissemination, and use of effective policies and practices.

Important Support: Programs Contributing to Innovation and Improvement

We recommend continued support for the following programs which will play an increasingly significant role in state and local improvement efforts.

- 21st Century Learning Centers
- Education for Homeless Children
- English Language Acquisition
- Even Start
- High School Graduation Initiative
- Improving Teacher Quality State
- Math Science Partnerships (ED)
- National Center Ed Statistics
- Parental Information. & Resource Centers
- Smaller Learning Communities
- Special Ed Research & Evaluation
- Statewide Data Systems
- Striving Readers
- Technology State Grants

Working Examples

Regional Educational Laboratories --- In 2005 the Regional Educational Laboratory – Central (McREL) supported the creation of “Balanced Leadership,” a three-year leadership development program using McREL research on effective school leaders. The research identified 21 responsibilities of principals that positively correlate with higher levels of school performance. Since its creation in 2006, more than 13,000 school principals nationwide have benefited from the program. Currently, the program is the subject of a major, IES-supported, randomized control trial being conducted in Michigan by Roger Goddard, a Texas A&M University researcher. Results from the study are expected in 2011.

Comprehensive Assistance Centers –Since 2007, the Mississippi Department of Education has received technical assistance support from the Southeast Comprehensive Center (SEDL) to address issues related to the over-identification of minority students for special education and the performance of students with disabilities on statewide assessments. SEDL partnered with the Southeast Equity Assistance Center and the Southeast Regional Resource Center to develop and implement statewide plans for response to intervention strategies (RTI) in Mississippi schools. Through this critical support the state has experienced 20% drops both in the total number of students identified with specific learning disabilities (SLD) and in the number of African-American students identified with SLD.

National Research and Development Centers --Two new studies from UCLA’s National Center for Research on Evaluation, Standards, and Student Testing (CRESST) have found that leadership and staff quality are the key factors in high quality afterschool programs. Researchers reported that the 53 high quality programs had overall positive effects on the day school program, including increased student effort and greater class

participation. The results were based on an evaluation of the U.S. Department of Education's 21st Century Community Learning Centers (CCLC). Study selection was from approximately 9000 CCLC afterschool programs and based on specific criteria set by a National Afterschool Partnership research partnership, coordinated by SEDL.

Unleashing America's Ingenuity

In total, we believe it has never been more important to expand the federally supported knowledge-innovation- improvement infrastructure and to deliver research-based solutions to schools with the greatest needs to improve. Congress is uniquely positioned to build on past efforts and lead us into a new era of innovation and transformation of our public school system.

Indeed now is the time to unleash America's ingenuity to solve our most pressing education problems, deliver break-the-mold solutions to our schools, and guide a new knowledge and innovation revolution in teaching and learning.

Thank you for your consideration.

James W. Kohlmoos

Jim Kohlmoos is the President and CEO of Knowledge Alliance, a non partisan non profit trade association in Washington DC dedicated to the effective use of research-based knowledge in education policy and practice. With three decades of experience in educational leadership and innovation in both the public and private sectors, Kohlmoos is charged with leading a national advocacy effort to expand support for evidence-based education and innovative, knowledge-based solutions in school improvement.

Prior to joining the Alliance in 2001, Kohlmoos was a vice president of Implementation Group, where over a two- year period as vice president he built an extensive bi-partisan government relations practice in elementary and secondary education. From 1993 to 2000 Kohlmoos served at the U.S. Department of Education as both a Deputy Assistant Secretary of Elementary and Secondary Education and as a Senior Adviser and Special Assistant. He also served on the Presidential Transition Team in 1992. From 1977 to 1993, he worked at the Close Up Foundation first as an instructor and director and then as vice president.

Kohlmoos began his professional career in education 1971 with the U.S. Teacher Corps in Salinas, CA. He subsequently served as a teacher trainer with the Peace Corps, which took him to Malaysia for three years.

Kohlmoos holds a baccalaureate in history from Stanford University (1971), plus teacher credentials from the University of California. He has completed graduate courses at Johns Hopkins University, George Washington University, and the University of California at Santa Cruz. A native of California, Kohlmoos has two adult children and resides in Arlington, VA, with his wife.

Mr. OBEY. Thank you very much. Appreciate your time.
Next, Chris Francis, Afterschool Alliance.

WEDNESDAY, MAY 12, 2010.

AFTERSCHOOL PROGRAMS

WITNESSES

CHRIS FRANCIS, CEO, YMCA OF THE NORTHWOODS, RHINELANDER, WISCONSIN, AFTERSCHOOL ALLIANCE, DEPARTMENT OF EDUCATION

JODI GRANT, EXECUTIVE DIRECTOR, AFTERSCHOOL ALLIANCE, DEPARTMENT OF ENERGY

Ms. GRANT. Good morning, Chairman Obey, members of the Subcommittee. It is an honor to be here today. I am Jodi Grant, Executive Director of the Afterschool Alliance. Afterschool programs are critical to America's next generation; keeping kids safe, inspiring them to learn, and providing a lifeline for working parents.

Thank you for your strong support of afterschool programs. This afternoon, more than 1.2 million children will be in afterschool programs supported by the 21st Century Community Learning Centers Fund. They are the lucky ones. They have access to a variety of exciting activities: CSI labs, robotics, theater, dance, art, music, and sports. Afterschool teachers make sure learning is fun and complements what the students are working on during the day.

Children in 21st Century Centers have access to a snack or supper, homework help, tutoring, and caring adult mentors. More than 15 million children remain unsupervised after the school bell rings. It is vital that this year's budget provide the additional resources that afterschool programs so desperately need.

I am delighted to introduce Chris Francis. Chris is the CEO of the YMCA of the Northwoods in Rhinelander, Wisconsin. Like many—

Mr. OBEY. Let me interrupt to say the staff listed it as Whinelander. It is Rhinelander. [Laughter.]

Ms. GRANT. Like many YMCAs around the Nation, Chris operates an afterschool program serving the needs of youth and families in the community.

Afterschool programs have been hit hard by this recession. Private funding sources have dried up and fees have gotten harder for families to pay. Federal funding has been essential in making afterschool available to many of the children that Chris serves and hundreds of thousands of them all across the Country.

The Administration's budget proposal for fiscal year 2011 carves out dollars from afterschool funding for other purposes, leaving some of our working parents and students behind. In addition, the blueprint for ESEA proposes to expand the priorities of the 21st Century Program in a way that would leave many more children without access to quality afterschool programs.

On behalf of the more than 26,000 afterschool programs that the Afterschool Alliance works with, we urge the Committee to appropriate additional funds for 21st Century this year and to make certain that it remains a dedicated funding stream for afterschool and summer programs in the years to come.

Chris.

Mr. FRANCIS. Good morning, Chairman Obey and Subcommittee members. I am Chris Francis and I am the CEO of the YMCA in Rhinelander, Wisconsin.

Let me start by thanking my member of Congress, Chairman Obey, for his decades of public service. He has served the people of Wisconsin honorably and we are grateful for all he has done for our region.

The YMCA provides the community and the school district of Rhinelander's sole afterschool chance program. We are almost entirely reliant on the district's 21st Century dollars. There are two multi-year grants at work, one for children grades 6 through 8 and one through grades 4 through 5. The district also applied for 21st Century dollars for K through 3, but was unfortunately not awarded a grant.

The first point I want to promote is that we work very hard to make sure our program is coordinated with what is going on in the regular school day. We have regular school day teachers who serve as tutors, and they have specific knowledge of what is being taught when and what extra help children might need.

At one of our centers, our site coordinator is also the school's guidance counselor, and she is vigilant about making sure we know which students need help with a given issue.

Over the course of the last year, students in our program have dramatically improved their grades. The average GPA of regular attendees has increased steadily from 2.5 in the first quarter to 3.2 the first quarter this year.

One of our afterschool students, whose name I will protect, came to us as a seventh grade student last year. He eventually had a run-in with law enforcement after school. That is the point at which a lot of kids can and do slip right through the cracks, labeled as troublemakers or low achievers. But the school district and the YMCA worked very hard with him to get his grades up and get him back on track, and this year he is on the honor roll and continues with our program because he enjoys it.

I know the Committee is interested in the opportunity that afterschool programs offer for delivery of health care services and health literacy instruction, and I could tell you that afterschool provides an ideal platform.

Now turning to a second to proposals going forward, I have some concerns. First, being a relatively small district, we do not have a professional grant writer on staff, so I am concerned about what it would mean if grants were nationalized.

Mr. Chairman, afterschool programs are in short supply. More than 300,000 kids are left unattended after school. Children in our State and in our Country deserve and need more afterschool programs.

[Written Statement by Chris Francis follows:]

Testimony of

**Chris Francis, CEO
YMCA of the Northwoods
Rhineland, Wisconsin**

Before the
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

House Appropriations Committee

May 12, 2010

On behalf of
The Afterschool Alliance



Good morning Chairman Obey, Ranking Member Tiahrt and subcommittee members. I'm Chris Francis, and I'm the CEO of the YMCA of the Northwoods in Rhinelander, Wisconsin. As Chairman Obey knows well, Rhinelander is a small, rural community of about 15,000 residents, about 60 miles north of Wausau, Wisconsin.

The YMCA of the Northwoods provides the community's sole afterschool program, and it is almost entirely reliant on its 21st Century Community Learning Centers grants. There are two multi-year grants at work, one for programming for children in grades 6 – 8, and one for students in grades 4 and 5. They expire in three and four years, respectively. The school district also applied for a 21st CCLC grant for K - 3 afterschool programming, but was not awarded a grant. The state only has so many 21st CCLC dollars. The grant recipient for the two grants we operate under is the School District of Rhinelander, which contracts with the YMCA of the Northwoods to provide services. Our YMCA is one of 2,676 YMCAs across the country serving children, youth and families; and the YMCA movement is the largest provider of child care and afterschool across our country.

I should mention, also, that I've worked in the afterschool field for several years now, running successful YMCA afterschool programs in Kentucky, Ohio, and Iowa, as well as in Wisconsin.

Our program in Rhinelander is young, but we're very proud of it because it's meeting such a critical community need. The program serves students at two school sites – the middle school (for grades 6 – 8) and the elementary school (for grades 4 – 5), as well as at the YMCA itself. I should mention, by the way, that the middle school has the second largest middle school population in the state.

The first point I want to stress about our program is that we work very hard to make sure our programming is coordinated with what's going on in the regular school day. We have regular school-day teachers who serve as tutors for our afterschool program. They have very specific knowledge of what's being taught when, and what kind of extra help children might need to keep up or get ahead. In addition to tutoring, a number of the teachers lead various enrichment classes in our program – everything from technology education, to cooking, to fishing lure-making, and more. The teachers are an integral part of what we're doing, and they help us keep connected to the regular school day in all kinds of ways.

In addition, at one of our two sites, our program director is also the school's Guidance Counselor, and she's vigilant about making sure we know which students need help with a given issue, which ones need extra skill-building, which ones are struggling in which subjects, and so on. As a result, we're able to target individual students with low reading or math skills, for example. And then our tutors provide the help they need, one on one, or in small groups.

We accomplish the same integration of afterschool and regular day at our other site, as well. Staff members there meet with teachers at the end of the day, every day, to find out about their assignments for the evening, identify problem areas, and so on.

In short, communication between our afterschool team and the regular school day teachers is absolutely vital to what we're doing, and we view our program as an extension of the regular day.

Our daily program begins with what we call a Power Hour, during which students do their school assignments for the evening, with supervision and help from our tutors and staff. That's also when they get individual or group tutoring. That includes a regular skill-building session led by one of our teachers. That hour is followed by a snack, and then the kids break into a variety of groups for enrichment classes, or take a bus to our YMCA facility to play games and sports. Next year we're going to beef up our STEM (Science, Technology, Engineering and Math) component. Two of our teachers took some additional training on the subject recently, and they're now developing a curriculum for next year that will include robotics, architectural drafting, and more.

All that effort has made a difference for our students' academic performance. Over the course of the last year, children in our program have gradually improved their grades. The average grade point average of regular attendees has increased steadily: from 2.5 in the first quarter of last year to 2.9 in the fourth quarter, and to 3.2 in the first quarter of this year. That's more than half a letter grade.

Mr. Chairman, as you know, we're a rural community with a fairly high poverty rate. About 45 percent of our kids are eligible for free or reduced-price lunches. About a fifth of the kids who attend regularly are at risk academically, and another 16 percent are special education children. Historically, we've had one of the highest drop-out rates in the state, and one of the lowest graduation rates. So we have a very high population of kids who need extra support afterschool.

Before our program was in place, a lot of those children – and others like them – went home to an empty house after the school day ended. Perhaps related to that, our high school has one of the highest pregnancy rates in the state. And there is no shortage of other inappropriate activities for kids to get involved in when left to their own devices, as I'm sure we all know. So getting our children into a safe, adult-supervised setting is a huge plus for them, as well as for their families, and the whole community.

If the principals of our schools were here, I know they would tell you that our program has also helped the larger school community. One of our ground rules is that parents need to come into the building at the end of the session to pick up their kids. They literally have to come in and sign them out. There's something about parents physically entering the school building that helps break down barriers. We also do family night events for children and parents, and recently had 106 people come to share some family time with us – in the building, seeing what the school's doing, hearing about our program, getting engaged. In short, the afterschool programming is helping connect parents who have in the past been disconnected from school.

One other aspect I want to note is that we have a truancy task force in place in the school district, and some of the students who've been skipping school are required by the court to come to our afterschool program as part of getting back on the path to regular attendance during the day. The reason for that is pretty simple: Afterschool is fun. Kids want to come, even the ones who've been truant. So it's pretty

common for the students who've been "assigned" to us by the Oneida County judges because they've been skipping school to stay with us long after their "assignment" has ended.

We have a similarly positive effect on student behavior across the broader population of afterschool students – that is to say, not just those assigned to us because of past truancy. Since we launched the program, suspension rates for the students in our program have decreased faster than for the rest of student population in general. So we have ample evidence that our program is having a very real impact.

One of our afterschool students, a young man whose name I'll keep to myself, came to us as a 7th grader last year. His family had just moved to the area, and he had a very rough transition. He didn't have any friends, struggled with his grades, and eventually got in trouble for stealing something. That's the point at which a lot of kids can slip right through the cracks – labeled as troublemakers, or low-achievers. But we worked very hard with him to get his grades up and to get him back on track, and this year he's on the honor roll, and continues with our program because he enjoys it. His attitude about school has turned around 180 degrees, and he's pretty close to a model student at this point. He's one of a number of success stories I could tell you about, the kind of story that makes my job so rewarding.

I know the committee is particularly interested in the opportunity that afterschool programs offer for delivery of health care services and health literacy instruction. And I can tell you that afterschool provides an ideal platform. First, we've got a student and parent population that would absolutely benefit from primary care services – we're rural, we have a lot of low-income families, and a lot who rely on seasonal employment and are therefore less likely to have insurance. Second, and I think most programs could say this, our program is very well suited to it. The second half of each day's program lends itself to modules of all sorts, so we could very easily accommodate health literacy education classes, and basic health screening or primary care services. We already incorporate some education around alcohol and drug abuse, and this would be a natural addition.

Moreover, it'd help strengthen the program, I expect, because it would provide yet another incentive for parents to enroll their kids, and because it would tighten parents' connection to the program, and our connection to the broader community.

In that respect, I think we're very similar to other afterschool programs around the state, so I think you'd be hard-pressed to find a program that couldn't provide a strong platform for health care and health literacy, provided that funding and the services were available to them.

I should note that one of Wisconsin's major health care providers has identified afterschool programs as an outstanding vehicle for providing preventive care and health literacy instruction. They've announced their intention to work with communities to bring prevention services to afterschool programs. That's a welcome development, and I'm confident programs would want to participate.

Now, turning for a second to the proposals for 21st CCLC going forward, I have some concerns. First, as I said, we are a small, rural community, and we don't have a professional grant writer on staff. So, I'm very concerned about what it would mean for us if the competition for 21st CCLC were nationalized. I think that would give large school systems a huge leg-up on the rest of us, especially small community based organizations.

And I'm also concerned about the idea of requiring that 21st CCLC grants go only to school districts. Ours does, and they contract entirely to us to provide services. But I think we're fairly unique in that regard. A lot of outstanding 21st CCLC afterschool programs are run by community-based groups, from YMCAs to faith-based organizations, to Boys & Girls Clubs, to extension services, to home-grown community organizations. They coordinate what they do with the schools, but they are the grant recipients and they provide very successful programs.

And the truth is that a lot of school districts are so strapped for dollars that they're cutting back on afterschool programs. Even when programs generate grant funding, the districts find that they cannot afford them. I can tell you that the YMCA takes a different view, and always has. Engaging kids in out-of-school time is what we were created to do, and it is and will always remain a core mission for us. I know other community groups share that commitment.

As many of you probably know, the YMCA focuses on character values – honesty, respect, responsibility, and caring. We incorporate those values into everything we do. We exist to serve the community, and that's why we run afterschool programs. Our three focuses are youth development, healthy living, and social responsibility – a perfect fit for afterschool.

Mr. Chairman, afterschool programs are in short supply in Wisconsin, despite the best efforts of many of us. According to the Afterschool Alliance's *America After 3PM* report, we've got more than 317,000 kids taking care of themselves in the afternoon hours – one third of the schoolchildren in the state. By contrast, just 11 percent of kids are in afterschool programs. If afterschool programs were more widely available, we'd have a lot of takers. The parents of 31 percent of the children not already in afterschool, representing more than 265,000 children, say they'd sign their kids up if one were available. And Wisconsin's story is similar to those of the other states, too. Afterschool programs are in too short supply. Too many children are left on their own.

As a representative of a community that has directly benefited from 21st CCLC, I encourage the committee to ensure that 21st CCLC funding remains dedicated to afterschool, before school and summer programs. Especially in this difficult economy, it is critical that funds for afterschool not be diverted to other purposes, which would result in even more kids left without afterschool programs.

Finally, I want to note that I came to the YMCA as a beneficiary of afterschool myself. I grew up in the foster care system, and lived in more than ten different homes when I was a kid. Afterschool programs were a source of great stability for me as a youth, and I hope in my work to provide that same stability

for today's children. And by the way, that includes my own kids, three of whom are enrolled in our program.

So I'm grateful for the opportunity to be with you today to tell you about the wonderful work that afterschool programs are doing for our children, and to ask that you do all you can to make sure that funding for afterschool programs continues and grows.

Thank you very much.

CHRIS FRANCIS

OBJECTIVE

PROFESSIONAL EXPERIENCES

2007-current YMCA of the Northwoods

- Chief Executive Officer

Direct oversight of a nearly \$3 million association with 3 branches and nearly 6,000 members.

Led this organization from a \$1.7 million to its current level in 2 years

Have secured nearly \$2 million in grants and almost \$2 million in estate and annual gifts.

Took our association from a \$60,000 annual campaign to its current level of \$180,000.

Have completely revised internal personnel policies and instituted many new programs.

Have created strong collaborations with many community agencies that did not exist prior to my arrival.

2006-2007 YMCA of Greater Cincinnati

- **Branch Executive Director, Kenton County YMCA**
- **Associate Executive Director, Community Services YMCA**

With the assistance of the District Vice President, developed the Community Services YMCA from a \$500,000 branch to a more than \$3.5 million branch in 3 years. Served in the capacity of Branch Executive.

Supervised a Full-Time staff of over 30 and a Part-Time staff of over 200 in 2 states (Ohio & Kentucky).

Led Annual Support Campaigns of \$64,000 with over 1,000 members and serving over 2,000 youth in various sports and afterschool programs

Programs include over 20 afterschool program sites, outdoor pool, swim team, water aerobics, swim lessons, day camp, full facility teen center, youth sports, flag football, baseball, soccer, lacrosse, cheerleading, basketball, etc., adult sports, Youth in City Government and other teen programs, CPR classes,

birthday parties, family programming and many more.

Our Ryland Heights Afterschool Program was just awarded the Excellence Award for being the top performing afterschool program in the state of Kentucky. This program serves 125 students or over 25 percent of the student body daily. Fifty percent of these students raised their math and reading scores by 1 entire letter grade.

Successful in breaking off a program site from its host YMCA (Community Services) with which we are in the process of planning a capital campaign for a new \$10 million facility.

Built strong boards from both branches simultaneously.

Extensive successful experience in grant writing, reviewing, and evaluating.

- **Ambassador, National Afterschool Alliance**

Selected to represent all afterschool programs from the state of Kentucky for a second 1-year term in Washington D.C. Was the first 2-term ambassador in the history of the program (served 1 term from Iowa). Responsibilities include advocacy to state and national legislators as well as dissemination of useful material to statewide afterschool programs.

2005-2006 Family YMCA of Black Hawk County

- **Branch Executive Director, Grundy Family YMCA**

Manage day-to-day operations of a 3-year-old branch YMCA. Duties included marketing, membership, finances, fundraising (Strong Kids Campaign), board and committee development, facilitating 3 fitness centers, personal training, adult and senior fitness classes, aquatics, youth sports, preschool movement classes, before and afterschool program, summer day camp, maintenance, custodial, etc.

Serve proudly as the longest director of this branch. We managed to double our membership and annual budget. When I left, our membership saturation was nearly 50%. We quadrupled our before and afterschool program and started a summer day camp in which we doubled participation in this program from the first year.

Maintain a significant volunteer base of over 50 people.

Renovated 2 classrooms in an old school building into 2 new state of the art fitness studios.

- **Head Varsity Boys and Girls Soccer Coach**

Activity contract with the Grundy Center CSD. Started a first year program for both teams. Was recognized for a very successful first season with many supportive letters to the editor in the local paper.

2003-2005 Area Education Agency 267
Waterloo and Cedar Falls Community School Districts

- **Director, ECHOES Afterschool Program**
21st Century Community Learning Center

Direct responsibility for a \$4 million Federal 21st Century Community Learning Center Grant in 4 extremely diverse middle schools and 2 junior high schools spanning 2 school districts and involving over 30 different agencies.

Led ECHOES from a small and very struggling over budget program to be the largest afterschool program in the State of Iowa.

Guided program to a 60% budget reduction while doubling, and in some cases, tripling program attendance. This resulted in an extension of an additional year of operation on existing grant funds.

Established budget requirements and supervision of, at one-time, 16 full-time staff and nearly 300 part-time staff for over 350 different 6th-9th grade academic, enrichment and recreational before and after school, summer, and weekend activities.

We served over 3000 students annually, or over 80% of all students enrolled in eligible grades in the two school districts. Minority students encompassed nearly 60% of all students served.

Continuous formal and informal marketing of program to include presentations at national and state conferences, state organizations, local civic clubs and businesses, to classes at the University of Northern Iowa, media, and all three school boards.

Negotiate contracts for services to local agencies.
2000-2003 Perry Community School District

- **P.A.C.E.S. Assistant Program Director**

P.A.C.E.S. (Perry's Academic, Cultural and Enrichment Services)
21st Century Community Learning Center

Assisted in the design, implementation and supervision of a \$1.6 million federal grant awarded to the school district partially due to Perry's diverse multi-cultural and socioeconomic population.

Established budget requirements and supervised staff for over 120 different K-12 and adult academic, enrichment and recreational before and after school and weekend activities, leagues and tournaments for three different buildings. Presented our program to three state and national conferences, community organizations and frequent presentations to the School Board.

2002-2003 (activity contract while in the Perry CSD)

- **Varsity Girls Head Soccer Coach**
- **Summer Swim Team Head Coach**

1993-2000 United States Navy

- **Hospital Corpsman**

Was accepted for training schools in 8 states in six years.

Awarded an ROTC scholarship to Iowa State University, given annually to a

very limited number of military personnel who apply.

Awarded Sailor of the Quarter 6 times and nominated Sailor of the Year once.

EDUCATION

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- | | |
|----------|---|
| Jan 2011 | Springfield College |
| | <ul style="list-style-type: none"> • Executive Masters Degree Candidate |
| May 1999 | Campbell University & Iowa State University |
| | <ul style="list-style-type: none"> • Bachelors of Health Science <p>Major in Health Science, Minor in Psychology & Naval Engineering. Completed degree in three years while serving full-time, active duty in the US Navy.</p> <p>Attended all functions required for an ROTC scholarship.</p> <p>Led junior Midshipmen in all areas of military preparation, physical fitness and academic improvement.</p> <p>Work study: Medical Assistant at the Iowa State University Health Clinic.</p> |
| May 1998 | Campbell University |
| | <ul style="list-style-type: none"> • Associates of Arts Degree |

PROFESSIONAL MEMBERSHIPS

-
- Rhinelander Rotary Club
 - Kenton County Rotary Club
 - Founding member of the Executive Board of the Kentucky Afterschool Network
 - Founding member of the Executive Board of the Iowa Afterschool Alliance
 - Grundy Center Kiwanis Club.
 - Grundy Center Lions Club.
 - Past Chair; Afterschool Task Force of Cedar Valley's Promise, a demonstration site of America's Promise
 - Member of the National Community Education Association
Was 1 of a committee of 3 to design the afterschool portion of the national conference the past 2 years, conferences attended by nearly 500 members.
 - Iowa Community Education Association
 - Waterloo noon Exchange Club
 - Waterloo Jaycees
 - American Legion

COMMUNITY ACTIVITIES

-
- Board of directors Rhinelander Chamber of Commerce
 - Board of Directors Rhinelander Ice Association
 - United Way Community Impact Team Member (review of agency proposals for delegation of funds)
 - Boy Scouts Advisory Council

- Founding member of the Perry Soccer Association
- Assisted youth in fundraising for a new \$150,000 skateboard complex and Band shell in Perry
- Youth Soccer coach for twenty years in six different states

VOLUNTEER EXPERIENCE

- Rhinelander Ice Association
- Pine Grove Community Church, Rhinelander
- Crossroads Community Church, Cincinnati
- Cedar Valley Community Church, Waterloo
Sunday School Teacher
Community Service Event Co-Coordinator
Small Group In-home Host
- Red Cross Disaster Relief Volunteer
- Member of the Big Brothers Big Sisters Program
- Youth mentor to two at-risk elementary school students
- Special Olympics Volunteer

AWARDS RECEIVED

- Excellence Award, Kentucky Department of Education
- Ambassador National Afterschool Alliance
- ECHOES Afterschool Program was awarded a Site of Promise by America's Promise
- Candidate for a 2002 Iowa Community Education Association Award.
- Kappa Delta Pi, An Honor Society in Education
- Dean's List: Campbell, Hardin Simmons, Iowa State, and the University of Wisconsin @ River Falls
- Sailor of the Quarter six times in six years of military service.
- Military letters of appreciation and commendation for community volunteer service, exceptional attention to detail, and exemplary medical service to the Marines of Camp Lejeune.

ACCREDITATIONS (EMERGENCY RESPONSE) OR DIRECTOR CERTIFIED

- YMCA Senior Director
- Volunteerism Trainer
- Program Management Trainer
- New CEO Institute
- Certified Personal Trainer
- Emergency Medical Technician (EMT)
- CPR Instructor
- Certified Surgical Technologist
- Preventative Medicine Certification
- Certified Lifeguard
- Certified Spinning Instructor
- Iowa High School Coaching Endorsement

- Leading People to Higher Performance
- Aquatic Management
- Training Others I
- YMCA Lifeguard
- Program Management
- Principals of YMCA Child Care
- Principals & Practices
- Youth Super Sports Director
- Fiscal Management and Budgeting
- Volunteerism: Living the Legacy
- Group Work
- 3 R's of Membership Development
- Foundations of YMCA Group Exercise
- Group Cycling Instructor
- Personal Training Instructor

REFERENCES AVAILABLE UPON REQUEST

Mr. OBEY. Thank you very much. Just one comment. You talk about kids who run into trouble with the law. When I was in the seventh grade, I skipped two days out of five regularly. I would get off the school bus—

[Laughter.]

I would get off the school bus, I would walk three miles home, grab my dog, go out and sit in the woods. If I had not had the intervention by a couple of teachers in what was the equivalent of an afterschool program, I might be in an institution, but it would not be the United States Congress. [Laughter.]

Mr. FRANCIS. Thank you, Mr. Chairman. We hear those stories a lot.

Mr. OBEY. Next, Sharon Washington, National Writing Project.

WEDNESDAY, MAY 12, 2010.

NATIONAL WRITING PROJECT

WITNESSES

SHARON J. WASHINGTON, EXECUTIVE DIRECTOR, NATIONAL WRITING PROJECT, DEPARTMENT OF ENERGY

MARY TEDROW, ENGLISH TEACHER, JOHN HENLEY HIGH SCHOOL, WINCHESTER, VIRGINIA, DIRECTOR, SHENANDOAH VALLEY SUMMER INSTITUTE

Ms. WASHINGTON. Good morning, Chairman Obey and other members of the Subcommittee. My name is Sharon Washington, Executive Director of the National Writing Project. I appreciate the opportunity to present this testimony requesting continued support. The National Writing Project is the only nationwide network of professional development centers dedicated to improving the teaching of writing. Since 1991, the National Writing Project has been an authorized program within the Elementary and Secondary Education Act. With consistent Federal funding, NWP has built a national infrastructure of more than 200 sites located in universities across the Country. NWP sites serve teachers at all grade levels and across disciplines; and teachers, schools, and districts across all 50 States, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

As you know, the Administration's fiscal year 2011 budget proposal recommends a competitive grants program for States called Effective Teaching and Learning: Literacy. NWP is not eligible to compete for funds in this consolidated program and would receive no direct funding. As a result, this effective national infrastructure that Congress has invested in since 1991 would be lost.

NWP professional development addresses two essential elements in educational improvement: the importance of quality teaching and the vital skill of writing. And today this means writing in all its forms—blog posts, tweets, persuasive essays, scientific and business writing, as well as digital stories, to name just a few.

In fact, writing in its many forms is the signature means of communication in the 21st century. In a 2009 national public opinion poll, three-quarters of those surveyed believe good writing skills are more important today than they were 20 years ago. And those

of us who have children, grandchildren, nieces and nephews, do not need to be convinced on that score.

Since 1974, the National Writing Project has expanded its capacity to work with teachers from one local site to more than 200 today. NWP is truly a national, innovative, effective program with a significant portfolio of research and evaluation studies that show impact on student writing and performance. Here are three key facts:

One hundred thousand teachers are served each year. Over the last decade, at least one million teachers have participated in our programs.

Two, National Writing Project's direct Federal support leverages a 1:1 match with university, local, State, and private dollars to improve classroom instruction in writing that reaches millions of students annually.

Three, NWP develops new innovative programs to support the work of local sites. For example, NWP has been awarded a three-year grant from the MacArthur Foundation to help support professional development programs using new digital tools for the teaching of writing.

We know how important it is for the next new generation of students to be able to communicate effectively and how important that will be to their futures. I would like to introduce to you Mary Tedrow, an English teacher at John Henley High School in Winchester, Virginia, the Director of the Shenandoah Valley Summer Institute.

Mary.

Ms. TEDROW. Thank you.

My initial contact with the NWP came in 1982, when I was a relatively new teacher and attended a professional development program featuring presentations by classroom teachers trained through the Northern Virginia Writing Project located at George Mason University. In an era when teachers worked in isolation, this was the first time teachers shared their best lessons and their student work with me.

This contact resulted in immediate changes to my practice, such as adding daily writing and student sharing, all unheard of in traditional classrooms.

In 1998, I was accepted into the five-week invitational summer institute. Since then, I have been able to extend the investment in my leadership to other teachers. Over 50 teachers in grades kindergarten through university have received training in the Shenandoah Valley since 2005 and returned to their respective districts to lead their peers in professional development, while continuing to learn new skills from the NWP network.

I have been exposed to more than 21 years of professional development programs, and the Writing Project stands alone in its transformative nature.

I thank you on behalf of Writing Project teachers from across the Country and the students that we teach each year.

[Written statement by Sharon J. Washington follows:]

**Written Testimony of Sharon J. Washington, Executive Director,
National Writing Project**

Submitted to the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies of the U.S. House Committee on Appropriations for Testimony on May 12, 2010.

I am Dr. Sharon J. Washington, the executive director of the National Writing Project (NWP). Since 1991, the National Writing Project has been an authorized program within the Elementary and Secondary Education Act (Title II, Part C, Subpart 2). With consistent federal funding, the NWP has built a national infrastructure that provides professional development for teachers in all 50 states, the District of Columbia, Puerto Rico and the U.S. Virgin Islands. NWP accomplishes this through a network of more than 200 linked project sites located in colleges and universities across the country. NWP sites are dedicated to providing the highest quality professional development in writing for teachers across all disciplines and at all grade levels.

I appreciate the opportunity to present this testimony requesting continued support for the National Writing Project. As you know, the Department of Education's (ED) proposed FY2011 budget includes no direct funding for NWP. Rather, it proposes to create a competitive grants program for states called Effective Teaching and Learning: Literacy. NWP would not be eligible to compete for funds in this program and would receive no direct funding. As a result, this effective national infrastructure that Congress has supported since 1991 would be lost. FY 2010 funding for NWP is \$25.65 million.

The National Writing Project addresses two essential elements in educational improvement: the importance of quality teaching and the vital skill of writing.

The impact of NWP professional development on teachers and their students

Numerous studies have pointed to the importance of quality teaching in student achievement. At the heart of the NWP model is the idea that effective and accomplished teachers can be leaders, and that they are pivotal to making positive changes in both teaching and in student achievement. The good news is that NWP has evidence of a positive impact on teacher practice and on student achievement. Independent surveys of 22,287 teachers, conducted over a seven-year period, indicate that teachers participating in NWP professional development endorse it as the best professional growth experience that they have had and they adopt practices that research has shown to improve student achievement in writing.

The NWP has also assembled a growing body of evidence derived from a national program of rigorous, independently-reviewed, quasi-experimental studies. In 16 different studies conducted between 2004 and 2010, researchers measured the extent to which students of teachers who received training by an NWP local site improved their writing skills. The studies were conducted in diverse settings representing all geographic regions of the country. Each study employed direct and independent assessments of student writing, and included carefully matched comparison classes or students.

**Written Testimony of Sharon J. Washington, Executive Director,
National Writing Project**

A team of external evaluators reviewed all of the research proposals for technical rigor. A panel of independent experts in writing assessment designed and oversaw the national scoring of student writing. In this independent scoring of student writing, NWP students' improvement outpaced that of students in closely matched comparison groups on overall writing performance in every one of the 16 studies. In one-half of these studies, the greater gains in Writing Project teachers' classrooms were so large as to be statistically significant.

In 2007, NWP contracted with SRI International to serve as an independent external evaluator for a five-year national randomized control study of the impact on writing instruction and writing performance of local Writing Project partnership activities with schools. The study focuses on teachers and students in seventh and eighth grades, although the entire school may participate in partnership activities. The study sample is comprised of 40 schools in diverse geographic regions throughout the country and data are being collected on a wide-range of teacher practices as well as student writing performance, including pre- and post-timed writing assessments. Results will be published in 2012.

The National Writing Project has also been shown to contribute to teacher retention—an important additional benefit of federal support for NWP. The NWP Legacy Study (NWP, 2007), which documented the careers of 2,114 teachers who participated in NWP Invitational Summer Institutes, found that 70% of NWP teachers remain in the classroom throughout their careers and 98% stay in education until they retire—and these teachers can be counted amongst the strongest and most accomplished who are serving in our nation's schools. This provides outstanding news in an era when many teachers leave the profession in their first five years. Additionally, the study found that Invitational Summer Institute participants serve an average of 22.7 years in education—more than 50% longer than teachers in general.

The importance of writing as a vital skill for all students

The NWP is the only federally funded professional development network that addresses writing at all grade levels and across all disciplines. Writing is a skill that is key to college and career readiness as well as to the practice of citizenship in a democracy. It is central across subject areas, as important to science and technology as it is to the humanities and vocational education. Today, as states and districts consider common standards for writing, the NWP stands ready to provide the professional development to teachers the country as a whole will need.

Direct federal funding of NWP ensures the availability of local partners who can work with locally defined, appropriate, and effective programs for educational improvement. It is an investment that leverages university, local, state, and private dollars to improve classroom instruction in writing that reaches millions of students at all grade levels annually. Direct funding is the spine on which these local investments are leveraged. The federal investment is matched one-to-one by these other investments.

NWP's national infrastructure provides a platform for innovation, as well as accountability, quality control, research, and the dissemination of promising and innovative teaching practices on a national scale. NWP programs include, for example, support for teachers across a variety of content areas to improve students' reading and writing for academic purposes, special programs

**Written Testimony of Sharon J. Washington, Executive Director,
National Writing Project**

for beginning teachers, and support for teachers using new digital tools in teaching writing. Through the NWP, tens of thousands of teachers are prepared to serve as a professional development resource to their colleagues and local schools. Total attendance at NWP local professional development programs is more than 130,000 educators each year.

Without federal support, NWP—the only national, federally funded program to focus on writing—would cease to exist. Local sites rely on federal support to maintain and grow local programs to meet local needs. Without federal support, most writing project sites would close, and therefore be unable to provide professional development to teachers in their states. The impact of the federal investment that has allowed the growth of the national network since 1991 would be lost.

The view from the classroom

The depth and breadth of the NWP have important implications for teachers. Northern Virginia Writing Project teacher, Mary Tedrow, explains the impact of NWP professional development on her growth as an English teacher and as a leader of other teachers. She is currently a high school teacher at John Handley High School in Winchester, Virginia, and the director of the Northern Virginia Writing Project Shenandoah Valley Invitational Summer Institute.

“I became a teacher in 1978 and my initial contact with the work of the National Writing Project came in 1982 through a course featuring presentations by classroom teachers trained through the Northern Virginia Writing Project, located at George Mason University. In an era when teachers worked in isolation, this was the first time teachers shared their best lessons and the work of their students with me. This initial contact resulted in immediate changes to my practice, including the inclusion of daily writing and student sharing, all unheard of in traditional classrooms.”

“I continued to seek out professional development opportunities offered by the Northern Virginia Writing Project until 1998, when I applied for and was accepted into the Writing Project’s five-week Invitational Summer Institute. I have been exposed to more than 21 years of professional development programs and the Writing Project stands alone in its transformative nature and longitudinal network of support.”

“The chief change in my instruction as an English teacher was a shift from assigning writing to teaching writing. All of my students consider themselves writers because they write daily and accept writing as a tool for thinking, reflection, and self-expression. Each year students are required to develop writing for a wider, public audience, bringing relevance and purpose to their writing. Many of these writings have been published in mainstream media, including national publications. Students have won scholarships, prizes, other tangible awards, or simply received a written response to inquiry. All these writing successes lead to confidence and further success. But their initial confidence begins with sharing with peers in the classroom. At one point in my career, five former students were simultaneously working on collegiate publications at the University of Virginia, Virginia Tech, Mary Washington, and Bridgewater College. Many of my former students are now earning their living as writers.”

**Written Testimony of Sharon J. Washington, Executive Director,
National Writing Project**

“In addition, the Writing Project taught me how to carry the lessons forward by modeling collegial sharing. I have been able to extend what I have learned to fellow teachers, serving as a resource to those in my school building and beyond. I have shared my own best practices in numerous settings, reaching hundreds of teachers in ten surrounding districts. By directing the satellite site for the Shenandoah Valley, I identify potential teacher leaders and shepherd them through their own presentation development, an inquiry process that deepens and extends teacher confidence and pedagogy. Over fifty teachers in grades K-University have received training in the Shenandoah Valley since 2005 and returned to their respective districts to lead their peers in professional development while continuing to learn new skills from the NWP network. Our teachers have developed and presented day-long programs for districts and a local university. In addition, our teachers share their classroom observations and resources through articles in education journals as well as our own publication, *The Journal of the Virginia Writing Project*.”

“I’ve worked with students in grades 9, 10, 11, and 12 and at all ability levels, self-contained special education to Advanced Placement and Dual Enrollment courses with our local community college—always using Writing Project-acquired skills with every student to great success in both motivating and engaging students so that real progress is made.”

“I credit the training received in the Writing Project for my students’ success and my ability to return to the classroom each year ready to work for improved literacy for all. I am still in the classroom because the NWP provides the resources, the network, and the energy to continually problem-solve for my diverse student population so I can provide them with relevant, meaningful writing and thinking experiences.”

The NWP makes an invaluable contribution to the country by working with teachers like Mary Tedrow so that they can prepare their students to be successful academically and in their chosen career paths. It also supports them as professional development leaders with their colleagues. Writing Project teacher-leaders design and deliver high-quality programs that have been demonstrated by research to be effective.

As the NWP executive director, I passionately support these efforts, and I urge Congress to continue its important investment in a program of national merit that has the potential to benefit all of America’s school children. A 2009 national public opinion survey revealed that writing is a priority for most of the American public. Three-quarters of those surveyed believe there is a greater need now to be able to write well than there was 20 years ago. Those of us who have children, grandchildren, nieces, and nephews do not need to be convinced on that score. We also know how important it is for the new generation of students to be able to communicate effectively and how important it will be to their future. We urge Congress not to allow the federal government’s only investment in this critical skill to be lost in preparing all young people for that future. The National Writing Project provides high-quality, large-scale, and cost-effective professional development programs for teachers so that our nation’s students will be accomplished writers and learners, as well as effective and engaged citizens in our democracy.

Sharon J. Washington
Executive Director
National Writing Project
Berkeley, CA

Sharon J. Washington, Executive Director of the National Writing Project (NWP), has nearly two decades of professional experience and scholarly work in social justice education, higher education administration, teacher preparation, outdoor recreation, sports, and the arts. Prior to joining the National Writing Project in 2008, Dr. Washington was the Interim Director of Faculty Equity Programs at the University of California Office of the President in Oakland, California. Before moving to California, she held a number of academic positions, including Special Assistant to the President for Diversity Initiatives at Bennett College for Women in Greensboro, North Carolina, and Provost and Vice President of Academic Affairs at Spelman College in Atlanta, Georgia. At Spelman, Dr. Washington worked closely with faculty on issues of governance and curriculum.

Throughout her career, Dr. Washington has demonstrated a strong commitment to the importance of high-quality literacy instruction for all students, and professional development for teachers across the K–16 spectrum. As the Founding Director of Project SPIRIT at Springfield College in Massachusetts, Dr. Washington developed an advising system that improved student retention and graduation, created a teacher preparation mentor program with K–12 teachers, and led a collaborative K–16 partnership that designed and implemented an academic enrichment program to encourage high school students of color to attend college.

Dr. Washington was a tenured member of the faculties at both Kent State University and Springfield College, and a visiting faculty member at University of Massachusetts at Amherst and the School for International Training in Brattleboro, Vermont. In addition, she was a Visiting Scholar in higher education administration in the Office of the President at the Massachusetts Institute of Technology.

Dr. Washington holds a PhD in education from The Ohio State University, a master's degree from Central Michigan University, and an undergraduate degree from The Ohio State University. Her recent writings focus on multicultural alliances and coping with the emotional and intellectual challenges of teaching about social justice.

 Education:

1999 **Master of Science in Education, Emphasis in Teaching**
Shenandoah University, Winchester VA

1977 **Bachelor of Arts in English/Journalism minor**
Shepherd College, Shepherdstown WV

Professional Licenses/Certification:

2001-2011 **National Board Certified Teacher: Adolescence and Young Adulthood English Language Arts**

1997- 2012 **Certified Journalism Educator**, endorsed by the Journalism Education Association
Kansas State University, Manhattan KS

1980-2014 **State of Virginia Post Graduate Professional License PGP-0602552**
Endorsements in English and Journalism

Fellowships/Internships:

2003-2004 **Washington Mutual Fellow for the Southeastern Center for Teacher Quality**. Raleigh, NC.

1998 **Fellow Northern Virginia Writing Project Invitational Summer Institute**
George Mason University, Fairfax VA

1996 **Teacher Intern** Winchester-Frederick County Economic Development, Winchester VA

Academic appointments:

2007- present **English Teacher, John Handley High School** Winchester Public Schools, Winchester, VA

2003-present **Co-Director Northern Virginia Writing Project** George Mason University, Fairfax VA
and **Director Northern Virginia Writing Project Shenandoah Valley Invitational Summer Institute**
Lord Fairfax Community College, Middletown VA

2003- present **Adjunct professor**, Lord Fairfax Community College, Middletown VA

1979-1982 and 1993-2007 **Secondary English and Journalism teacher**
Milbrook/James Wood High School, Frederick County Public Schools, Winchester VA

1978 **Substitute Teacher** Frederick County Public Schools, Winchester VA.

Honors and Distinctions:

2005 Nominee VEA Virginia Educator

2004 Nominee USA All-Teacher Team

2003 Teacher Leader Fellow for the Southeastern Center for Teaching Quality

2001 Frederick County Teacher of the Year

2001 Wal-Mart Teacher of the Year

2001 Recognized in Winchester Star Series "Who Inspires You?" by former student.

Virginia Department of Education Database of Exemplary Teachers

1991-1992 Winchester Friend of Education

1999 Governor's Gold Award for Physical Fitness

Mr. OBEY. Thank you both very much.
Next, Sheriff Dean Roland, from Fight Crime: Invest in Kids.

WEDNESDAY, MAY 12, 2010.

CHILD CARE AND DEVELOPMENT BLOCK GRANT PROGRAM, HEAD START PROGRAM, AND 21ST CENTURY COMMUNITY LEARNING CENTERS PROGRAM

WITNESS

DEAN ROLAND, SHERIFF, BURNETT COUNTY, WISCONSIN, FIGHT CRIME: INVEST IN KIDS

Mr. ROLAND. Thank you for the opportunity to testify before you today. My name is Dean Roland, and I am the Sheriff of Burnett County, Wisconsin. I am also a member of Fight Crime: Invest in Kids, a national organization of more than 5,000 law enforcement leaders who have come together to take a hard-nosed look at the research about what really works to keep kids from becoming criminals. Fight Crime: Invest in Kids takes no Federal, State, or local money, and does not run any of the programs we advocate for. I know from my experience and from research that access to high-quality early care and education for at-risk kids cannot only help close the achievement gap, but prevent crime and make our communities safer as well.

For example, a study found that at-risk kids left out of Chicago's Child Parent Centers Early Education Program, similar to Head Start, were 70 percent more likely to be arrested for a violent crime by age 18. Another study found that at-risk kids left out of the high-quality Perry Preschool Program were five times more likely to be chronic offenders, with five or more arrested by age 27. By age 40, those who did not attend the Perry Preschool Program were more than twice as likely to become career offenders, with more than 10 arrests and twice as likely to be arrested for violent crimes.

Head Start is the Nation's premier school readiness program for children in poverty. Head Start incorporates most of the key features of high-quality, early education programs proven to cut crime, such as appropriate class size and teacher-student ratios, comprehensive and age-appropriate early learning standards, related services, including health referrals, and parent involvement and coaching.

Research shows Head Start works for kids. For example, one national study found that Head Start increases high school graduation rates by 7 percent for children in the program compared to their siblings not in the program, but in other care, and decreased crime by 8.5 percent.

Early Head Start provides comprehensive child development and family strengthening services for infants and toddlers from birth to age 3. Research shows that Early Head Start is effective. A study of over 3,000 families participating in 17 Early Head Start programs nationwide found that three-year-olds who had participated in Early Head Start had higher levels of cognitive and language development, better attention to play, and lower levels of aggressive behavior.

This finding on aggressive behavior relates directly to crime. Research shows that 60 percent of children with high levels of disruptive, aggressive behaviors in early childhood will manifest high levels of antisocial and delinquent behavior later in life.

High-quality early care and education for at-risk kids not only reduces crimes, but saves the public money as well. For example, a cost-benefit analysis of the high scope Perry Preschool Program showed that it saved \$16 for every \$1 spent. And having been in this profession 35 years and 20 years as a professional, I can tell you you cannot build enough jails. We need to focus on the education. Prevention works.

Unfortunately, despite these proven benefits, these programs remain chronically underfunded. Nationally, Head Start is only able to serve about half of the eligible kids. Early Head Start serves less than 5 percent of eligible infants and toddlers.

The Child Care and Development Block Grant is only able to help one in seven eligible low-income kids get high quality child care. In the current economic climate, more kids need these services, but are unable to access them, and States are cutting back their early care and education investments due to their budget shortfalls.

To ensure at-risk kids get the high quality, early care and education they need, I strongly urge you to increase funding for investments that have been proven to reduce later crime and violence by helping kids get the right start in life.

As you develop the fiscal year 2011 appropriations package for the Department of Labor, Health, and Human Services, I urge you to fund President Obama's proposed increase of nearly \$1 billion over fiscal year 2010 levels for Head Start and Early Head Start, and to increase funding for the Child Care and Development Block Grant by \$1 billion over fiscal year 2010 levels. As a law enforcement officer who has watched too many kids grow up and become criminals, I know these investments will make our community safer.

Thank you again for this opportunity.

[Written statement by Dean Roland follows:]

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5,000 Police Chiefs, Sheriffs,
Prosecutors, other Law Enforcement
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Preventing Crime and Violence

U.S. House of Representatives

Committee on Appropriations

Subcommittee on Labor, Health and Human Services, and Education

Written Testimony of:

Sheriff Dean Roland
Burnett County Sheriffs Department
Siren, Wisconsin

On Behalf of:

FIGHT CRIME: INVEST IN KIDS

Submitted for the Record:

April 16, 2010

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to submit this testimony. My name is Dean Roland and I serve as Sheriff of Burnett County, Wisconsin. I am also a member of FIGHT CRIME: INVEST IN KIDS, a national anti-crime organization of more than 5,000 police chiefs, sheriffs, prosecutors, attorneys general, other law enforcement leaders, and victims of violence who have come together to take a hard-nosed look at what really works to keep kids from becoming criminals.

As a sheriff, I know there is no substitute for tough law enforcement and dangerous criminals need to be locked up. But I also know that arrest and incarceration alone will not reduce our communities' crime problems. My own experience tells me, and research proves, that targeted investments in kids that help them get the right start in life can help prevent them from turning to gangs, drugs, and crime in the future.

My colleagues from FIGHT CRIME: INVEST IN KIDS and I appreciate the difficult job this Committee faces in allocating scarce resources in the face of enormous fiscal challenges. But in these difficult times we cannot afford to short-change programs that have been proven to work. Now more than ever, our families and communities need these programs. Further, our future safety, and our Nation's long-term fiscal well-being, will be improved through these crucial investments.

Early Childhood Care and Education

A child's earliest years are crucial to his or her development. High-quality early care and education for at-risk kids during those critical early years not only can help close the achievement gap, but reduces the child's likelihood of committing a crime later in life, as well.

For example, at-risk kids left out of Chicago's Child-Parent Centers, government-funded early education programs similar to Head Start which served 100,000 three-and-four-year-olds, were 70 percent more likely to be arrested for a violent crime by age 18, according to a study published in the *Journal of the American Medical Association*. The study also found that those left out were 67 percent more likely to be held back a grade in school, and 71 percent more likely to have been placed in special education.

Another study, conducted by Schweinhart, et al. in 1993, found that at-risk kids who were left out of high quality High/Scope Perry Preschool program were five times more likely to be chronic offenders with five or more arrests by age 27. By age 40, those who did not attend the Perry Preschool program were more than twice as likely to become career offenders with more than 10 arrests, and twice as likely to be arrested for violent crimes. Further, children left out of the program were four times more likely to be arrested for drug felonies by age 40, and seven times more likely to be arrested for possession of dangerous drugs. Children who participated in the Perry Preschool program were 44 percent more likely to graduate from high school compared to those left out of the program.

Another nationally recognized program, North Carolina's Smart Start, helps working parents pay for early child care and improve the quality of care through educational opportunities, resources, and educational materials for teachers. Researchers studying early education centers with Smart Start's quality improvement assistance found low-income children who were not enrolled were twice as likely

to have behavior problems such as aggressive acts and poor temper control, anxiety, and hyperactivity in kindergarten.

Head Start is the nation's premier school readiness program for children in poverty. Since 1965, it has provided voluntary, comprehensive education, social and emotional development, and physical and mental health services, as well as parent involvement efforts.

Research shows Head Start works for kids. Although a recent national study of Head Start found that the initial positive impacts of Head Start participation on language and literacy skills diminished by the end of first grade, other studies that followed Head Start children into adulthood, and long-term studies of other pre-kindergarten programs, have found notable long-term impacts. For example, one national study found that Head Start increased high school graduation rates by 7 percent for children in the program compared to their siblings not in the program but in other care, and decreased crime by 8.5 percent.

Head Start incorporates most of the key features of high-quality early education programs proven to cut crime, such as appropriate class-size and teacher-student ratios, comprehensive and age-appropriate early learning standards, related services (including health referrals), and parent involvement and coaching. That being said, it is imperative that we continue to make sure Head Start is incorporating the newest research and proven approaches to ensure the program is realizing the full potential that the early education research shows is possible. We note that, since that study was done, Head Start Reauthorization passed calling for important improvements, such as increasing the number of teachers who must have Bachelor's degrees. In recent years, Congress has taken great strides towards improving the quality of the program and reaching more of the eligible kids — that progress needs to continue on both fronts.

Early Head Start, created in 1994, provides comprehensive child development and family strengthening services for infants and toddlers from birth to age 3. Early Head Start provides these services through center-based, home-based, and combination program options.

Research shows that Early Head Start is effective. A randomized control study of over 3,000 families participating in 17 Early Head Start programs nationwide found that three-year-olds who had participated in Early Head Start, compared to their peers who did not, had higher levels of cognitive and language development, better attention to play, and lower levels of aggressive behavior (Love 2005). This finding on aggressive behavior relates directly to crime—research shows that sixty percent of children with high levels of disruptive, aggressive behaviors in early childhood will manifest high levels of antisocial and delinquent behavior later in life. Early Head Start also helps parents. Parents who participated in the program demonstrated more emotional supportiveness to their children, provided higher levels of language and learning stimulation, and read to their children more.

The evidence showing the crime-reducing impact of high-quality early care and education for at-risk kids is compelling, but I must also point out that these investments save the public money. For example, a cost-benefit analysis of the High/Scope Perry Preschool Program showed that it saved \$16 for every \$1 spent (Schweinhart 2005).

Unfortunately, despite the proven benefits, years of chronic underfunding have resulted in overwhelming unmet need for high-quality early childhood care and education. Head Start is only able to serve about half of eligible children nationwide, while Early Head Start serves less than 5 percent of eligible infants and toddlers. The Child Care and Development Block Grant is only able to help 1 in 7 eligible low-income kids. The current economic climate only makes the problem worse: more kids are eligible for these programs and in need of these services but unable to access them, and states are cutting back their early care and education investments due to their budget shortfalls.

To ensure at-risk kids get the high-quality early care and education they need, I strongly urge you to increase funding for investments that have been proven to reduce later crime and violence by helping kids get the right start in life. **As you develop the FY 2011 appropriations package for the Departments of Labor and Health and Human Services, I urge you to fund President Obama's proposed increase of nearly \$1 billion over FY 2010 levels for Head Start and Early Head Start, and to increase funding for the Child Care and Development Block Grant by \$1 billion over FY 2010 levels.** The President's Budget Request proposed a \$1.6 billion increase in mandatory and discretionary funding for CCDBG in FY 2011.

As a law enforcement leader who has watched too many kids grow up to become criminals, I know these investments will make our communities safer. Thank you again for the opportunity to submit this testimony.

Personal Biography

Dean W. Roland, Sheriff
Burnett County, WI

Employed in the profession of law enforcement since 1976.

Graduate of the Los Angeles County Sheriff's Academy, Class 185

Employment History;

Glendora Police Department, Glendora, CA 1976 – 1983
Kootenia County Sheriff's Department, Coeur d' Alene, ID 1983 – 1985
Idaho Department of Law Enforcement, 1985 – 1995
Juvenile Justice, Warden, Coeur d' Alene, ID 1996
Siren Police Department, Chief, Siren, WI 1997 – 2002
Burnett County Sheriff's Department, Sheriff, Siren, WI 2003 to present

Educational History;

Fullerton State University, Fullerton, CA – Educated in Music, Secondary Education
Lewis/Clark State Collage, Coeur' d' Alene, ID – Interdisciplinary studies / Communication
Boston University, School of Medicine / School of Public Health – Fellow, "Join Together Leadership Institute", Funded through the Robert Wood Johnson Foundation

Throughout my professional career I have had the opportunity to be affiliated with numerous prevention coalitions on the local, regional, state and national levels. I have experienced first hand, the positive results of proper expenditure of prevention designated funds in curbing crime, incarceration of offenders and turning non-productive individuals into productive, law abiding, contributors to communities and society.

Mr. OBEY. Thank you very much, and I appreciate the work you have done through the years.

Mr. ROLAND. Thank you very much.

Mr. OBEY. Thanks for coming.

Mr. ROLAND. Same to you.

Mr. OBEY. Next, Ford W. Bell, American Association of Museums.

WEDNESDAY, MAY 12, 2010.

AMERICAN ASSOCIATION OF MUSEUMS

WITNESS

**FORD W. BELL, PRESIDENT, AMERICAN ASSOCIATION OF MUSEUMS,
INSTITUTE OF MUSEUM AND LIBRARY SERVICES**

Mr. BELL. Thank you, Chairman Obey and Ranking Member Tiahrt—who is not here—and other members of the Subcommittee. I appreciate the opportunity to testify today. I am here on behalf of the American Association of Museums to request your support for an increased investment in our Nation's museums. The American Association of Museums is proud to represent the full spectrum of our Nation's museums, from aquariums, botanical gardens, and historic sites, to planetariums, presidential libraries, science and technology centers, zoos, aquariums, and everything in between, along with professional staff and volunteers who work for and with museums.

The Institute of Museum and Library Services is the primary Federal agency that supports the Nation's 17,500-plus museums, and its Office of Museum Services awards grants to all types of museums to help museums care for their collections and to create innovative programs and exhibits.

We urge your support for \$50,000,000, a \$15,000,000 increase for the Office of Museum Services at the Institute of Museum and Library Services.

Museums are essential to our communities, schools, and economy for many reasons. Each dollar that supports museums is an important economic investment. In 2008 alone, museums contributed approximately \$20 billion to the American economy. Museums also serve as economic engines, bolstering local infrastructure and encouraging tourism. There are 850 million museum visits in the United States every year.

Museums create jobs. An estimated 500,000 people currently work for museums, but the more than \$20 billion pumped into the American economy by museums creates millions more jobs.

Museums are also key partners in education. Museums spend more than \$2.2 billion annually on educational programming for K through 12 children and design educational programs in coordination with State and local curriculum standards in almost every subject. They also provide professional development for teachers in all subjects.

Through the use of digitization and traveling exhibitions, museums are able to bring their collections to underserved regions across the Country. Unfortunately, like so many other nonprofits, museums are struggling in this economy. They have been forced to

cut back hours, programming, community services, and, therefore, jobs. Some have had to close their doors for good.

It is for these reasons that increased funding for the Office of Museum Services, which has been essentially flat-funded for many years, is so critical. For example, Congressman Obey, in your district, IMLS grants support Lac Courte Oreilles Band of Lake Superior Chippewa Indians Malagasy Cultural Resources Center, allowing the Center to partner with the local schools to develop regional history curriculum.

Congressman Rehberg, in your district, with IMLS support, the great Museum of the Rockies will host Dinosaurs Under the Big Sky through its new Mesozoic Media Center. This multi-partner project will bring science to entirely new audiences with live webcasts and other educational programming.

It is important to note that zoos and aquariums are critical members of our museum family. They are leaders in environmental education; they are saving endangered species; and they too are economic engines creating thousands of jobs and spurring local tourism dollars. I raise the issue today because a year ago zoos and aquariums were excluded from competing for stimulus funds and are currently excluded from some proposed jobs bills.

Museums are significant job creators, and zoos and aquariums, in particular, create green jobs. They are science education jobs, keep us competitive globally, and they are investments in community infrastructure that we cannot afford to ignore. I urge the Subcommittee to consider the vital role that zoos and aquariums play as any further stimulus bills or jobs bills or other appropriations bills are considered.

Thank you for the opportunity.

[Written statement by Ford W. Bell follows:]



May 12, 2010

Testimony of

**Dr. Ford W. Bell, DVM,
President,
American Association of Museums
www.aam-us.org
Washington, DC**

**to the House Appropriations Subcommittee
on Labor, HHS and Education and Related Agencies**

SUMMARY OF TESTIMONY:

Dr. Bell will be testifying:

- in support of \$50 million for the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS);
- to ensure that zoos and aquariums are treated fairly in relation to jobs bills, stimulus bills, or other spending bills; and
- to express concerns about the proposed elimination and consolidation of certain programs at the U.S. Department of Education.

Chairman Obey, Ranking Member Tiahrt, and members of the Subcommittee, thank you for inviting me to testify today. I am here on behalf of the American Association of Museums to request your support for an increased investment in our nation's museums.

The American Association of Museums (AAM) is proud to represent the full range of our nation's museums – including aquariums, arboretums, archaeological museums, art museums, botanical gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, nature centers, planetariums, presidential libraries, science and technology centers, zoological parks, and other specialty museums – along with the professional staff and volunteers who work for and with museums. Our membership is as diverse as the collections contained in the museums we represent.

The Institute of Museum and Library Services (IMLS) is the primary federal agency that supports the nation's 17,500+ museums, and its Office of Museum Services (OMS) awards grants to all types of museums to help museums digitize, enhance and preserve their collections; broaden their reach into schools and communities; provide educators with professional development; and create innovative, diverse, cross-cultural and multi-disciplinary programs and exhibits.

We urge your support for \$50 million – a \$15 million increase – for the Office of Museum Services at the Institute of Museum and Library Services (IMLS). This independent federal agency is funded within the Labor, Health and Human Services and Education appropriations bill.

To be clear, museums are essential in our communities for a variety of reasons:

Each dollar that supports museums is an important economic investment. According to the 2009 Museum Financial Information Survey, museums contributed approximately \$20.7 billion to the American economy in 2008. Museums also serve as economic engines, bolstering local infrastructure, and spurring tourism. In fact, cultural and heritage activities account for more than 23% of all domestic tourism. Both the U.S. Conference of Mayors and the National Governors Association agree that cultural assets such as museums are essential to attracting businesses, a skilled workforce, and local, regional, and international tourism, with the U.S. Conference of Mayors finding, "The arts, humanities, and museums are critical to the quality of life and livability of America's cities."

Museums create jobs. An estimated 500,000 people currently work for museums, but the more than \$20 billion pumped into the American economy by museums creates millions more jobs. Unfortunately, in the past year, many museums have had to lay off employees because, like so many other non-profits, museums are being forced to cut back on hours, educational programming, community services and, therefore, jobs.

Museums are key partners in education. The educational role of museums is at the core of their service to the public. They spend more than \$2.2 billion annually on K-12 educational programming and receive approximately 90 million visits each year from primary and

secondary school students. In fact, museums offer educational programs in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography, and social studies, in coordination with state and local curriculum standards. And they reach beyond the scope of instructional programming for schoolchildren by also providing professional development for educators.

Museum collections are at serious risk. According to the 2005 *Heritage Health Index*, at least 190 million artifacts are suffering from light damage and harmful and insecure storage conditions. OMS grant funding helps to ensure that museums and their collections can continue to play a vital role in the preservation and interpretation of our cultural and natural heritage.

Museums are struggling in this economy. At a time when many families cannot afford to travel and school resources are strained, museums are working overtime to fill the gaps – providing more than 18 million instructional hours to schoolchildren and offering free or reduced admission. But some are struggling just to keep their doors open, and others have shut down altogether. Museums are further being squeezed by state and local budget cuts, limiting public access to some of our nation’s treasured collections.

Digitization and the use of traveling exhibitions bring museum collections to underserved populations. Teachers, students, and researchers benefit when cultural institutions are able to increase access to trustworthy information through online collections and traveling exhibits. Most museums, however, need more help in digitizing collections to meet this need. This is especially important when geographical distance prevents travel to a wide range of museums.

Grants to museums are highly competitive and decided through a rigorous, peer-reviewed process. But because the Office of Museum Services has been essentially level-funded in recent years, only a small fraction of the nation’s museums are currently being reached, and many highly rated grant applications go unfunded each year. For example, in 2009:

- Only 11 of the 34 African American History and Culture grant applications were funded.
- Only 22 of the 35 Native American/Native Hawaiian Museum Services grant applications were funded.
- Only 7 of the 59 21st Century Museum Professionals grant applications were funded.
- Only 167 of the 433 Museums for America grant applications were funded.
- Only 80 of the 193 National Leadership grant applications were funded.
- Only 35 of the 129 Conservation Project Support grant applications were funded.

Conservation Project Support is especially important as more and more museums struggle to protect and preserve their collections. According to the 2005 *Heritage Health Index*, 59% of museums have collections damaged by light; 56% have insufficient security to protect their collections; 80% do not have an emergency plan that includes collections; 71% need additional training and expertise for staff caring for collections; and only 13% have access to endowment funds for preservation.

Funding for the Office of Museum Services has benefits far beyond that of simply serving museums; these grants help teach the local school curriculum, create jobs, promote cultural

diversity, preserve our national heritage, educate our communities, promote cultural tourism, and bolster the local economy. This is particularly important at a time when individual, corporate, and foundation giving has declined considerably. Here are a few examples from your Congressional districts:

- In Wisconsin's 7th district, the New Visions Gallery received a grant to create a permanent exhibition using objects of African art. The Lac Court Oreilles Band of Lake Superior Chippewa Indians has received IMLS grants in support of its Migizi Cultural Resources Center to both create public programs and partner with the local schools to develop curriculum around the region's history. The Leigh Yawkey Woodson Art Museum received an IMLS grant to evaluate the condition of more than 1,300 works in the museum's permanent collection. The Bad River Band of the Lake Superior Chippewa Indians has also received IMLS grants to develop the historical context of the tribe, including the Town of Odanah, and to establish a cultural center.
- In Kansas' 4th district, an IMLS grant supported the Water Center, Wichita's interactive water education museum which incorporates interactive panels and graphics to explain the science behind water and the causes of pollution.
- In Alabama's 1st district, the Gulf Coast Exploreum Science Center received a grant in support of FUNDamental Physics, an innovative program designed to introduce science to underserved target audiences. At a time when science education is key to our global competitiveness, this program will inspire curiosity about basic science that is encountered every day. Also in Alabama, the Poarch Band of Creek Indians have received grants in support of the Calvin McGhee Cultural Center, which is preserving and digitizing its collections and ensuring that its staff has the necessary expertise to handle the sacred objects and historical documents housed at the Center.
- In California's 9th district, the Habitat Children's Museum created an interactive outdoor space and natural environment for exploring nature and science. The Children's Hospital and Research Center at Oakland created a "Hall of Health" to facilitate a Medical Mystery Festival and a multicultural health fair, along with "The Brainiacs," a science discovery theater. The Peralta Hacienda Historical Park demonstrates how museums of all kinds are helping to teach the state curriculum. Its IMLS grant supported three important yet very diverse programs: the Fourth Grade School Field Trips Program for classes studying the state-mandated California history curriculum; the Community Docent Program in which elders - many from Asia, Latin America, or the American South - tell their stories as tour guides; and the Community Leaders Stewardship Program, in which local youth learn about history and cultures as they grow, cook, and share produce. The Oakland Museum of California received a grant to help integrate cultural diversity more fully into the long-range plans. The University of California Botanical Garden's "Crops of the World" garden is educating elementary school students, in both English and Spanish, about sustaining soil fertility through composting and crop rotation.

- In California's 15th district, the City of Gilroy received a very small grant, just \$2,256, to preserve two important portraits that will hang in the museum's main gallery to illustrate the overall needs of the collection and show how preserving these artifacts will help preserve the stories of Gilroy. The de Saisset Museum at Santa Clara University received a grant to conduct a detailed conservation survey of more than 5,000 works of art, including Renaissance and Baroque prints.
- In California's 34th district, the Japanese American National Museum used IMLS grants to develop and implement an oral histories project with 5 neighboring states - Arizona, Colorado, New Mexico, Texas, and Utah. This project actively engaged teachers, scholars, community members and education/cultural institutions in developing K-12 education curricula tailored to each state's needs.
- In Rhode Island's 1st district, IMLS grants have supported the John Brown House, the Little Compton Historical Society, the Preservation Society of Newport County, the Newport Art Museum, and the Rhode Island Historical Society. The Newport Art Museum grant supports the expansion of MUSE, a school-to-career program that teaches high school students about the day-to-day operations of museums and cultural institutions through mentoring, hands-on and classroom learning, and site visits.
- In Connecticut's 3rd district, the Peabody Museum of Natural History received an IMLS grant to engage New Haven students in grades 8-12 (many from groups that are traditionally underrepresented in the sciences) in a science literacy program combining hands-on projects, field trips, and college preparation. The Connecticut Children's Museum received an IMLS grant to infuse the museum with a layer of inclusive elements to broaden access for children with special needs.
- In Minnesota's 4th district, the Tamarack Nature Center, the Science Museum of Minnesota, the Minnesota Children's Museum, and the Minnesota Historical Society have all received IMLS grants. One of the Science Museum of Minnesota's projects involves digitizing its Ojibwe and Dakota collections.
- In Montana, the Museum of the Rockies will host "Dinosaurs Under the Big Sky" through live webcasts and other educational programming. Through the new Mesozoic Media Center, this multi-partner project will bring sciences to whole new audiences. The Holter Museum of Art received a grant to preserve a number of works through the purchase of new storage materials. The Yellowstone Gateway Museum of Park County is using a grant to catalog, duplicate, and archive the museum's extensive collection of photographs, which covers 100 years of regional history. The Yellowstone Art Museum, through an IMLS grant, will continue its role as a leading provider of art education services in the community, which has had a direct impact on the regional school curriculum. The People's Center Museum, the tribal museum of the Confederated Salish and Kootenai Tribes, also received an IMLS grant to create a traveling exhibit of photographs and narratives.

- In New York's 17th district, the Lower Hudson Conference of Historical Agencies created a professional training program for museum professionals at the 165 historic house museums in the Hudson Valley region. The Historical Society of Rockland County received a small grant, just \$3,000, to improve the way its collection is stored to both preserve the artifacts and make them more easily accessible.
- In Oklahoma's 4th district, the Sam Noble Museum of Natural History received an IMLS grant to improve its storage of the museum's late 19th century specimens. The Comanche Nation of Oklahoma also received an IMLS grant to promote the development of Native American museum workers from southwest Oklahoma. The Greater Southwest Historical Museum also received an IMLS grant to hire and maintain full-time curatorial staff members who are charged with cataloging, protecting, identifying, and preparing objects for inclusion in an online exhibit.

It is important to note that zoos and aquariums are critical members of the museum family. They are leaders in environmental education, they are saving endangered species, and they too are economic engines, creating thousands of jobs and spurring local tourism dollars. I raise this issue today because just one year ago, zoos and aquariums were unfairly excluded from competing for stimulus funds, and are currently excluded from some proposed jobs bills.

I understand difficult choices must be made in this economic climate, but I strongly believe that supporting zoos and aquariums is a wise investment in our future. Museums are significant job creators and zoos and aquariums, in particular, create green jobs. They are science education jobs that keep us competitive globally, and they are investments in community infrastructure we cannot afford to ignore. I urge the subcommittee to consider the vital role that zoos and aquariums play as any further stimulus bills, jobs bills, or any appropriations bill are considered.

I also want to express my concerns about the proposed elimination and consolidation of certain programs within the U.S. Department of Education. In an effort to enhance accountability and effectiveness, the Administration has proposed consolidating a number of programs authorized under the Elementary and Secondary Education Act. The Administration's proposed \$265 million for its Effective Teaching and Learning for a Well-Rounded Education would consolidate several programs of critical importance to schools and the museum field - Arts in Education, Foreign Language Assistance, Teaching American History, and Civics Education.

The American Association of Museums wholeheartedly supports a well-rounded education and is proud to have museums partnering with schools nationwide to teach the local curriculum, but we must ensure that any efforts to alter support for these vital areas of study – no matter how well-intentioned – does not compromise the integrity of programs related to arts, foreign language, history, civics, and economics.

Thank you once again for the opportunity to testify today. I am happy to answer any questions you may have.

Ford W. Bell, DVM
President, American Association of Museums

Ford W. Bell began his tenure as president of the American Association of Museums in June 2007. He brings to AAM a lifelong passion for museums, and a clear understanding of the important role which museums play as places of lifelong learning and inspiration.

Bell has a longstanding relationship with the museum community. He helped raise \$103 million as co-chair of the Minneapolis Institute of Arts' "Bring Art to Life" capital campaign, completed in 2006 and he served as chair of the organization's board from 2003 to 2005. His grandfather, James Ford Bell, was a leading supporter of the Institute, and also of the Museum of Natural History at the University of Minnesota, renamed in his honor in 1966. Ford Bell served on the Advisory Board of the Bell Museum from 1983 to 2007. A board-certified veterinary oncologist, Bell credits his many childhood visits to the Bell Museum with fostering a lifelong love of nature and science.

Bell has more than 30 years experience as a nonprofit executive, board chair, donor, trustee and educator. A candidate for the U.S. Senate in 2006, he was president and CEO of the Minneapolis Heart Institute Foundation, a prominent clinical cardiovascular research organization and a nationally recognized provider of community heart health education.

From 1982 to 1995, Bell served on the staff of the University of Minnesota's College of Veterinary Medicine, where he taught and did clinical research in comparative oncology. He has advocated for science learning, conservation and community health initiatives through his affiliation with a wide range of organizations, including Project EarthSense and the JASON Advisory Committee, a public-private elementary and secondary school science education initiative. He served as trustee and elder at Westminster Presbyterian Church in

Minneapolis, and co-chaired that institution's \$16 million capital campaign. From 1993 to 2007, he served as chair of the James Ford Bell Foundation. An educator for much of his career, Bell also served as a trustee of Connecticut College in New London, CT from 1998 to 2007.

A native Minnesotan, Bell is married and has four children. He lives in Potomac, MD.

AAM was founded in 1906 to represent the entire museum field. Today AAM has some 18,000 members, including 3,000 museums, zoos, aquariums and public gardens. Its stated mission is "to enhance the value of museums to their communities through leadership, advocacy, and service." The largest museum organization in the world, AAM serves the field by promoting standards and best practices; gathering and sharing knowledge; and providing advocacy on issues of concern to the museum community.

Mr. OBEY. Thank you. Let me just make one point. Zoos were not excluded because there is anything wrong with zoos; they were excluded because it was necessary to find the votes to pass the stimulus bill. There are some people in this institution and out who have a habit of demagoging when they can find anything they can get a handle on, and they certainly have done so in the past with respect to those institutions, which is why, for the greater good, we regretfully had to recognize that the power of their outlandish rhetoric outweighed our ability to counter it, to be frank about it.

Mr. BELL. I understand, Congressman. Thank you, Mr. Chairman.

Mr. OBEY. Thank you.

Next, Vivian Schiller, National Public Radio.

WEDNESDAY, MAY 12, 2010.

NATIONAL PUBLIC RADIO

WITNESS

VIVIAN SCHILLER, PRESIDENT AND CEO, NATIONAL PUBLIC RADIO, CORPORATION FOR PUBLIC BROADCASTING

Ms. SCHILLER. Thank you, Mr. Chairman and members of this Subcommittee. I appreciate your giving me the opportunity to express support for funding for public broadcasting. As the President and CEO of NPR, I am testifying today on behalf of more than 850 public radio station partners, producers, and programming allies, including American Public Media, Public Radio International, and Public Radio Exchange.

The public radio system, all in public broadcasting, and the tens of millions of Americans who listen and watch every week are grateful for your decades of support. We are also grateful for the additional \$25 million in funding provided by Congress last year to help stations offset the devastating financial impact of the Country's economic crisis.

The concept of public funds for public broadcasting is a cornerstone of the relative financial stability of our system. In the few minutes I have with you today, let me cover two closely related topics: the dramatic changes that have engulfed media, and particularly the world of journalism and news that are the strengths of public radio; and the state of public radio and steps we have taken.

Last month, the Project for Excellence in Journalism from Pew released its annual State of the News Media Report. Every year it is a very hotly anticipated document and, at 700 pages, it is pretty closely analyzed for clues and nuances about the future of the business. Well, usually it is tea leaf reading, but not this year. This year, the report came like a blow to the head with a two-by-four.

Here are a few phrases I pulled verbatim from the State of the Media Report: enormous losses; grim revenue numbers; continued declines in audience; continued declines in revenue; continued declines in staff; and this line, the losses suffered in traditional news gathering in the last year were so severe that, by any accounting, they overwhelmed the innovations in the world of news and journalism.

Here are these findings translated into numbers. Newspapers, including online, saw ad revenue fall 26 percent during the past year, bringing total losses over the last three years to 41 percent. Nearly one in every five journalists working for newspapers in 2001 is no longer doing so. Almost 6,000 full-time newsroom jobs were cut, or about 11 percent in 2008. Sixteen hundred jobs lost in local television the last two years. Over the past five years, newspaper audiences have declined by 29 percent. And on and on.

This is coverage of the very issues that you referenced as so needing of support, a lot of things that are being talked about today. This is coverage about health care, about education, about worker protection, about children in need and children at risk.

I add one more statistic that really begins to tell the story or, rather, leaves the story untold: overseas, all three television networks had, by the end of 2008, eliminated the posting of a full-time reporter in Iraq. The Pew report begins with two words: What now?

First, you should know that we are NPR still have our Iraq bureau and a full-time bureau in Kabul, Islamabad, and 14 other international locations, plus 21 domestic bureaus. Yes, we were hit by the recession and suffered losses, mostly in underwriting revenue, but we have not hit in audience. We have just reached an all-time high: 34 million listeners every week to NPR member stations at six hours per week. Our audience continues to grow.

So here is the what now for us. We are moving forward through innovation and partnership in three areas: more original reporting, foreign investigative breaking news, and particularly local reporting; reaching more diverse audiences to reflect changes in each race and ethnicity as the demographics of the Country change; and fully embracing new platforms and technologies—streaming, podcasting, use of the iPhone, iPad, BlackBerry; wherever our audience needs us.

And unlike others in media seeking to turn a profit or charge fees for access to the news, we will always be free to our audience, the American people. NPR believes public radio and all of public broadcasting have an integral and primary role to present the future information needs of American communities, and we thank you for our support today. Thank you.

[Written statement by Vivian Schiller follows:]

Statement of Vivian Schiller, President and CEO
 NPR
 April 12, 2010

**Subcommittee on Labor, Health and Human Services, Education and Related Agencies
 U.S. House Committee on Appropriations**

Fiscal Year 2011 – 2013 Appropriations for the Corporation for Public Broadcasting

Thank you Chairman Obey and Congressman Tiahrt for this opportunity to support funding for public broadcasting. As NPR's President and CEO, I am testifying on behalf more than 850 public radio station partners, producers and distributors of public radio programming including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX), and many stations, both large and small that create and distribute content through the Public Radio Satellite System (PRSS).

The public radio system and the tens of millions of Americans who listen to public radio programming every week are grateful, Chairman Obey, for your decades of support for public broadcasting funding. We are also grateful for the additional \$25 million in funding provided by Congress last year to help stations offset the devastating financial impact of the country's economic crisis.

Public radio's service to America is a story of continuing success, increasing dedication to news, journalism, public affairs and cultural programming, and expanding deployment of technology to improve our reach and impact. The nearly 34 million people tuning weekly into public radio programming is more than the total combined circulation of *USA Today*, the *Wall Street Journal*, *The New York Times*, *Los Angeles Times*, *The Washington Post*, and the next top 62 newspapers. We are serving the American public through our broadcast stations, through our websites and internet streaming and through applications for the iPhone, iPad, Droid, Blackberry and other mobile devices.

Consider the contributions made by these public radio stations whose local public service illustrates a system-wide commitment to community engagement:

- **Milwaukee Public Radio:** This station began broadcasting public service programming in 1964 on 89.7 FM. Since that time it has become Southeastern Wisconsin's premiere source for news, information and entertainment programming with more than 100,000 listeners tuning in each week and with more than 20,000 unique visitors per month to the station's web site. While most listeners still tune to the station's FM frequency, others are discovering WUWM on new digital media platforms. Broadcasting with HD digital sound quality, WUWM provides two channels of programming, both on-air at 89.7FM and on-line at www.wuwm.com. 89.7 FM / HD1: IN-DEPTH NEWS broadcasts locally-produced in-depth news, quality entertainment, and cutting-edge music, as well as the best national offerings from NPR, Public Radio International and American Public Media. WUWM2/HD2: THE DEUCE, is a unique 24/7 music-intensive format that can be heard on HD Radio or streamed on-line. Podcasts of local programs are also available. *Lake Effect* is the station's daily magazine, which includes interviews, reports and documentaries on issues and culture in southeastern Wisconsin. WUWM also produces several music programs that bring progressive music to the air such as *Café Tonight*, *Saturday at the Café*, and *It's Alright, Ma, It's Only Music*. WUWM is listener-supported, licensed to the University of Wisconsin Board of Regents and has 30 full time staff including 11 journalists.

- **WXPR:** A community-licensed public radio station with studios in Rhinelander, WXPR serves about a 70-mile diameter area of Wisconsin. On the air since 1983, WXPR would never have been built, nor continued to serve the local community today without the continuing effort and generosity of many people in the Northwoods, plus Community Service Grants from the federal appropriation provided to the Corporation for Public Broadcasting. WXPR is proud to provide the only radio service to large, sparsely populated rural areas of the state and is planning to expand coverage with two small repeater stations in Ironwood and Iron Mountain, Michigan.
- **Southern California Public Radio:** Southern California Public Radio is a member-supported public radio network that operates 89.3 KPCC-FM in Los Angeles and Orange County, 89.1 KUOR-FM in the Inland Empire and 90.3 KPCV in the Coachella Valley. Reaching more than 600,000 listeners every week, SCPR is the most listened to public radio news service of any kind in Southern California. With about 30 reporters, and bureaus in L.A., Orange County, the Inland Empire and Washington, D.C., the station offers a wide array of rich local programming, including: *L.A. Theatre Works*, *The Loh Down on Science* and *Town Hall Journal*, all designed to serve the unique local needs of its community.
- **Minnesota Public Radio:** MPR operates a regional network of 38 stations, covering Minnesota and parts of Wisconsin, the Dakotas, Michigan, Iowa and Idaho. With 850,000 listeners each week, MPR has the largest audience of any regional public radio network and an expanding news department of 76 that is committed to improving local and regional coverage. MPR is a leader in classical and current music, and in a growing online news service, NewsQ.

Stations like these, operating in every state and congressional district in the country, have become living embodiments of journalistic excellence, providing news, information and cultural programming as other sources of media are contracting or retreating from local coverage. Many are the only locally owned and operated news organization in their community.

Public Funds for Public Media:

The Corporation for Public Broadcasting (CPB) is an indispensable public funding source for public radio, accounting for roughly 12% of an average public radio station's annual budget. The public broadcasting community is urging Congress to appropriate \$604 million in two-year advanced funding for FY 2013.

Journalism, news, information and cultural programming are the cornerstones of public radio. And we are expanding in these areas, as many commercial news organizations contract. For example, public broadcasting stations have launched **Local Journalism Centers (LJCs)**, combining funds from CPB and resources of 27 station entities to expand and improve journalism on the regional level. A primary goal of this initiative is to replace some of the traditional newsgathering capacity that has been lost amid the recent cutbacks, to take full advantage of developing technology in order to nourish and support the creation of new journalistic endeavors, and to ensure that there are no barriers to the distribution of public media content.

A second recent joint initiative – Project Argo – is aimed at bringing expanding information on topics critical to communities and the nation. This project, supported by CPB and the John S. and James L. Knight Foundation, provides a pilot group of 12 NPR stations with the resources to expand original reporting, and to curate, distribute and share online content about high-interest, specialized subjects. The two-year pilot will help a dozen stations establish themselves as definitive sources of news on a topic selected by each one as most relevant to its community, such as city politics, the changing economy,

healthcare, immigration and education. These online reports will help fill the growing gap in local news offerings.

Importantly, music is an integral element of public radio's community service and the future of public media. Classical, jazz, folk, AAA, world and eclectic are music formats offered by public radio stations in cities large and small. Communities like Boston, New York, Philadelphia, Pittsburgh, Cincinnati, Miami, Washington, D.C., Los Angeles, McAllen Texas, Rochester New York, Grand Rapids Michigan, Tulsa Oklahoma, Knoxville Tennessee and the entire states of Wyoming, Minnesota and Vermont, among others, depend on public radio stations as the only source of classical music. For jazz enthusiasts, public radio stations in cities like Newark, Ypsilanti, Laramie, Baton Rouge, Phoenix, Los Angeles, Denver, Orlando, San Mateo, Montgomery, Worcester, Atlanta and Las Vegas are gateways to the masters of this uniquely American musical dialect. More than 100 stations have full-time music formats.

DIGITAL FUNDING:

Broadcasting's Digital Transition

Broadcasting remains the principle distribution path for public radio programs. By the end of 2009, 463 stations were on the air with digital signals and more than 180 were multicasting (sending out two or more program streams) to their communities and listeners. Recent action by the Federal Communications Commission permitting public radio stations to boost HD signal power and provide expanded signal coverage creates another compelling reason to continue conversion funding. Many public radio stations will be seeking to boost power to better serve their communities in the coming year. Public broadcasting's funding request to continue our digital transformation in FY 2011 is \$59.5 million.

Public Radio is using digital broadcasting as a tool to improve and broaden the reach of our programming to poorly served and un-served audiences. Radio reading services for the blind and deaf are becoming more accessible. Stations' service to communities during times of local and regional emergencies will benefit from digital broadcasting's more flexible and adaptable features. Digital broadcasting technology has enabled public radio stations to:

- **Provide increased local services to communities:** Stations are doubling and tripling programming offerings by multicasting through HD radio channels 2 and 3 options while super-serving existing and new groups of listeners.
- **Increase the diversity of programming by providing additional content for current audience:** Use of HD radio channels 2 and 3 means more news programming options, music and entertainment for listeners. The additional HD radio channels allow stations to add public affairs programming, educational instruction, international news, specialty music streams (jazz, classical, bluegrass, folk, rock, pop, international, etc.), and non-English language news.
- **Bring the content rich world of public radio to blind and deaf audiences:** Relying often on small armies of volunteers, over 120 stations provide 24-hour life-line service consisting of news education and readings from daily newspapers and magazine articles. Text information services such as emergency warnings and public service alerts may also be incorporated into the signal to enable display of this data.

The New Network: Internet, Web and Mobile Platforms

The 1967 Public Broadcasting Act gave enduring reality to two important concepts: public funds for public broadcasting and the creation of a national, independent, not-for-profit network of television and radio broadcasters to serve the American public. More than four decades later, as public

broadcasting's embrace of new technologies to serve and engage a wider and more diverse audience quickens its transformation into Public Media, a new network for the digital era must be fostered. This new network, built upon a *Public Media Platform* and utilizing the success and assets of public broadcasting as its core, will enable the next generation of content creation and distribution so that the American public can benefit from a larger vision of service from Public Media.

Public radio is embracing the networked environment as a primary platform for audience and community service. To ensure that the American public continues to have free and universal access to public media content, high-speed and affordable broadband access is simply a necessity. Congressionally-appropriated digital transition funds are essential to help ensure our success in providing a larger, more diverse and more inclusive service to the American public.

Among the many station and national network initiatives underway, these are worth highlighting:

- **NPR's API:** In July 2008, NPR released an open Application Programming Interface, (API), a new pathway for content and functions to be widely shared on the web. NPR was one of the first major national media organizations to launch an API and it is an integral component of our mission to create a more informed public. It allows public radio stations and individual users to play a direct role in broadening web access to public radio content. The principle of openness encompassed in this web tool is a fundamental extension of the standards of free and universal access that are common to more traditional distribution of public radio content. Utilization of the API by stations enables the creation of content that more closely matches local community needs and interests, and facilitates diverse, more creative presentations of content, again to connect local information needs with content generated by other, collaborating communities.
- **The Public Media Platform:** Realizing public media's full potential requires a strategic investment in an information architecture that brings together fragmented digital assets. The *Public Media Platform*, under development by NPR in partnership with CPB, APM, PRI, PBS and the Public Radio Exchange (PRX), will allow content from a wide variety of independent and institutional producers to be combined in a common back-end system; and then for that content to be extracted and displayed on a wide variety of digital platforms based on business rules set by the producers. It is in essence and in practice the digital equivalent of the satellite distribution network that serves public radio's broadcast audience with the powers of search, social media tools, analytics and data.

Thank you again for continuing to support funding for public service media.

Vivian Schiller, President and CEO of NPR

A media executive and journalist with 25 years experience in the industry, Vivian Schiller joined NPR as President and CEO in January 2009. Schiller leads all NPR's worldwide media operations, including the organization's partnerships with a network of more than 900 public radio stations, and their service to the nearly 30 million people who listen to NPR programming.

In her role, Schiller is charged with assuring the fiscal, operational and journalistic integrity of NPR, building the organization and revenue base to further the public service mission of the NPR member network. As a strong advocate of innovation, she is a key driver in leveraging new technologies to advance NPR's core mission and grow audience for all of public media.

Schiller's vision for the future of public radio is one that has at its core the unique and powerful relationship NPR has with our member stations. Her clear and strong commitment to the importance of partnership in public service journalism – with NPR's stations, listeners, and others in public media – is a hallmark of her presidency.

Since assuming her President and CEO role, NPR not only continues to receive the highest honors in excellence in journalism, but has also garnered attention of media critics and earned recognition in the mobile and digital space. Under her leadership, NPR was named in 2009 and 2010 by *Fast Company Magazine* as one of the World's Top 50 Most Innovative Companies in Media and cited as an Innovation All-Star for 2010. As NPR's first female CEO and one of very few women running who have ever run a large news organization, Schiller was listed as one of Washington, DC's Most Powerful Women by both *Working Mother* and *Washingtonian Magazine*.

Prior to joining NPR, Vivian Schiller served at The New York Times Company as Senior Vice President and General Manager of NYTimes.com. Schiller led the day-to-day operations of NYTimes.com, the largest newspaper website on the Internet, overseeing product, technology, marketing, classifieds, strategic planning, and business development.

Previously, Schiller spent four years as Senior Vice President and General Manager of the Discovery Times Channel, a joint venture of The New York Times and Discovery Communications. Schiller launched the network, and under her leadership, Discovery Times Channel tripled its distribution while achieving critical acclaim for its award winning journalistic programming.

Schiller also served as Senior Vice President of CNN Productions, where she led CNN's long-form programming efforts. Documentaries and series produced under her auspices earned multiple honors, including three Peabody Awards, four Alfred I. DuPont-Columbia University Awards, and dozens of Emmys.

Schiller began her career as a simultaneous Russian interpreter in the former Soviet Union, which led her to documentary production work for Turner Broadcasting.

As NPR's President, Schiller is an ex officio member of the NPR Board and serves as Chairman of the National Public Media Board. In a volunteer community service role, Schiller also serves as co-Chair of the National Literacy Project.

Schiller resides in Bethesda, MD, with her husband and two children.

Mr. OBEY. Thank you.
Next, Yasmina Vinci, from the National Head Start Association.

WEDNESDAY, MAY 12, 2010.

HEAD START

WITNESS

YASMINA VINCI, EXECUTIVE DIRECTOR, NATIONAL HEAD START ASSOCIATION

Ms. VINCI. Chairman Obey and distinguished members of the Committee, thank you very much for the opportunity to testify.

Chairman Obey, given your recent announcement of your pending retirement, I would like to take a very quick moment and thank you for all you have done as Chairman of the Committee, and I think early care in education is stronger as a result of your efforts. Thank you.

I am testifying today on behalf of the National Head Start Association, which represents more than one million children, 200,000 staff, and 2600 programs in the United States.

Created in 1965, Head Start is the evidence of the Country's longest commitment to early education and care. Head Start programs across the Country prepare young high-risk children and their families to succeed in school and in life.

These investments in Head Starts have paid dividends to the children, to their families, and to the communities. Reliable research studies demonstrate that fewer Head Start children repeat grades; fewer need costly special education; more graduate from high school.

Because of Head Start's health services, 33 to 50 percent fewer children die of preventable diseases in their early school years. And as you heard from Sheriff Roland, Head Start benefits society at large by reducing crime and its cost to crime victims.

More than 27 million children have benefitted from Head Start. But prior to the American Recovery and Reinvestment Act, Head Start was only able to serve about 40 percent of eligible children and Early Head Start served only 2 to 3 percent. Thanks to Congress, through the Recovery Act funding, Head Start and Early Head Start have been able to serve 14,000 more three- and four-year-olds, and 50,000 more infants and toddlers across the Country.

However, the increased numbers of children and families now assisted by Head Start still falls short of the need. According to the U.S. Bureau of Census, another 1.1 million children under the age of six slipped into poverty between 2001 and 2008, and those children are now on Head Start programs' waiting lists.

For instance, in Sedgwick County, Kansas, there were over 2,000 applications for only 237 spaces. In five Minnesota communities, 1,866 families are on waiting lists. And in just one program in California, Berkeley-Albany YMCA, 240 families are waiting anxiously every day for a space to open.

For all of these reasons and more, NHSA strongly supports the President's budget for fiscal year 2011. Specifically, the President's budget provides an additional \$989 million for Head Start and

Early Head Start to continue to serve the 64,000 additional children and families funded by the Recovery Act.

The President's proposal would allow Head Start programs to preserve the recent gains. After years of flat funding that did not keep up with the rate of inflation, we are moving towards paying Head Start staff wages consistent with their skills.

Through the Recovery Act, an additional 24,000 jobs were created for the new Head Start staff. Thousands more jobs were created in building new Head Start classrooms and playgrounds, and many more children and families are being served.

Accordingly, it would be devastating to every community across the Country if Head Start suddenly had to cut back and reduce the size of the program. Tens of thousands of early childhood professionals would have to be laid off; at-risk families would be dropped from the program with nowhere else to turn; buildings would sit empty; and the gains that have been made would be lost. This Country cannot afford for that to happen.

For all these reasons and more, National Head Start Association hereby requests that this Committee support the President's fiscal year 2011 budget proposal for Head Start and for the other early childhood programs as well.

Thank you very much.

[Written statement by Yasmina Vinci, follows:]



Testimony of Yasmina Vinci

Executive Director of the National Head Start Association
Alexandria, Virginia

Before the House Appropriations Committee's
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Regarding FY 2011 Budget Priorities

Public Witness Hearing on Wednesday May 12, 2010 at 10:00 a.m.

Testimony Summary:

Ms. Vinci's testimony addresses the need for adequate appropriations for Head Start programs under the Office of Head Start, Administration for Children and Families, U.S. Department of Health and Human Services.



Testimony of Yasmina Vinci, Executive Director of the National Head Start Association,
Before the Appropriations' Subcommittee on Labor, Health and Human Services, Education and Related
Agencies, May 12, 2010 at 10 a.m.

Chairman Obey, Ranking Member Tiahrt, Members of the Subcommittee, thank you for the opportunity to testify about the critical needs of Head Start and Early Head Start (collectively "Head Start") in the context of the fiscal year 2011 Budget and Appropriations.

Chairman Obey, given the recent announcement of your pending retirement, I would like to take a quick moment to especially thank you for all you have done in Congress and at the helm of this Committee for years. Early childhood education and care is stronger in this country because of your efforts.

The National Head Start Association ("NHSA") is a private not-for-profit membership organization dedicated to addressing the needs of Head Start children and their families. We are proud to represent more than 1 million children, 200,000 staff, and 2,600 Head Start programs in the United States.

As you well know, Head Start, created in 1965, is evidence of the country's longest commitment to early education and care. As the leading programs for high risk children and families in the country, Head Start and Early Head Start provide comprehensive education, health, mental health, nutrition, and parent involvement services to low-income children between the ages of birth and five and to their families as well.

Dedicated to vulnerable children and families who need intensive assistance to achieve the American dream, Head Start programs across the country help children and their families to succeed by preparing them for school and for life. Not only does Head Start provide high-quality early education by a racially and ethnically diverse workforce of talented teachers and teachers' assistants, but its family service workers help Head Start families solve problems associated with unstable housing and jobs. Head Start's health workers assure that Head Start children receive necessary early periodic screening, diagnosis, and testing services, follow-up care, and vaccinations. They also assist in children getting needed dental and mental health services. Head Start parents learn best practices in parenting and become active partners in their children's education. Many Head Start programs also help parents find job-training programs and support their efforts in the workforce.

Importantly, these investments in Head Start pay dividends of many types. These Head Start dividends include scholastic preparation, improved health outcomes, and reductions in crime. For example, reliable studies demonstrate that Head Start children experience increased achievement test scores and favorable long-term effects with decreased grade repetition and reduced need for special education in

elementary and secondary schools.¹ Econometric analysis also suggests that Head Start reduces the high school drop out rate.² Additionally, recent research reports that Head Start reduced the mortality rates for 5- to 9-year-old children to the national average for all 5- to 9-year-old children (Head Start rates were 33 to 50 percent lower than for comparable children who were not enrolled in Head Start).³ Along with improving the health of its children and families, Head Start benefits its children and society at large by reducing crime and its costs to crime victims.⁴ Head Start children are significantly less likely to have been charged with a crime than their siblings who did not participate in Head Start.⁵ All of these outcomes and more demonstrate that Head Start works.

More than 27 million pre-school aged children have benefited from Head Start programs so far. Graduates of Head Start are in the workforce and in public service positions in practically every community. But prior to the American Recovery and Reinvestment Act (the "Recovery Act"), Head Start was only able to serve about 40 percent of eligible children and families. Early Head Start served even fewer, only about 2 to 3 percent of the eligible population. Thanks to Congress, however, the Head Start community has been able to extend the program's reach and to help more struggling families as the country continues to deal with an uncertain economy. Through the Recovery Act funding, Head Start and Early Head Start have been able to serve 14,000 more three- and four- year olds and 50,000 more infants and toddlers across the country. Head Start has also added approximately 24,000 more jobs in areas that did not exist before.

These Recovery Act gains are especially important, not only because the program now provides necessary supports to more families in need, but also because when children are served in Head Start programs, their parents know that they are safe, well-cared for, and in good hands. With this peace of mind, Head Start parents can join the workforce or participate in job training programs, as this newly enrolled mother of two school-age children as well as a 6-month old in Oakland CA tells: *"When I found out I was excepted [sic] into the home-based option I was excited! It was like there was an angel watching out for this new baby. I have so little income! I am in school and my husband does not make enough. He is also in school finishing his degree. We want to be in a better spot you know! We want to complete our degrees so we can build something and be better off in the long run. I could not have done this without this support. Knowing I have the chance to enter into the center option when my baby is old enough helps. I will take it! I will volunteer and give back to the program. This is just good for families."*

However, the increased numbers of children and families now assisted by Head Start and Early Head Start services still fall short of meeting the need for Head Start services in many communities. According to the U.S. Bureau of Census, another 1.1 million children under the age of 6 slipped into poverty

¹ Barnett, W. S. (2002, September 13). The Battle Over Head Start: What the Research Shows. Presentation at a Science and Public Policy Briefing Sponsored by the Federation of Behavioral, Psychological, and Cognitive Sciences; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-Term Effects of Head Start. *American Economic Review*, 92 (4): 999-1012.

² Ludwig, J. and Miller, D. (2007). Does Head Start improve children's life chances? Evidence from a regression discontinuity design. *The Quarterly Journal of Economics*, 122 (1): 159-208.

³ *Id.*

⁴ Fight Crime: Invest In Kids. (2004). Quality Pre-Kindergarten: Key to Crime Prevention and School Success. Available at <http://www.fightcrime.org/> on July 23, 2004, 1.

⁵ Garces et al. (2002, September). Longer-Term Effects of Head Start, 999-1012.

between 2001 and 2008⁶ and those children are now on Head Start programs' waiting lists. (In Sedgwick County, Kansas, there were over 2,000 applications submitted for only 237 Head Start and Early Head Start spaces. In 5 Minnesota communities alone, 1,866 families are on waiting lists. In Berkeley, CA, at just one program – Berkeley-Albany YMCA, 240 families are waiting anxiously every day for a space to open.) Programs throughout the country are stretching to cope with increased health care costs for staff—for instance in Helena, MT where on July 1st there will be a 20% increase in providing health insurance (\$45,000) for the 248-child, 54-staff program.

For all of these reasons and more, NHSA strongly supports the President's Budget Proposal for fiscal year 2011 that was released in February of this year. It provides critical support for young children and their families and preserves recent gains made for these individuals by building on the historic increases provided by Congress through the Recovery Act. Specifically, the President's budget provides an additional \$989 million for Head Start and Early Head Start (beyond FY 2010's Appropriation) to continue to serve the 64,000 additional children and families funded by the Recovery Act.

The President's Budget Proposal also provides an additional \$1 billion for the Child Care and Development Fund in preparation for reauthorization to sustain child care gains, and improve health, safety, and outcomes for children. This amount will allow States to avoid cuts to families now accessing child care and NHSA supports these additional child care funds as well.

The President's Budget Proposal would allow Head Start programs to preserve the many recent gains made. After years of flat funding that did not keep up with the rate of inflation, we are moving towards paying Head Start staff wages that are consistent with their skills which will hopefully keep them working in Head Start programs, rather than having to look elsewhere for better paying jobs. Through the Recovery Act, additional jobs were created for new Head Start staff. Large infrastructure investments in local communities for new Head Start classrooms and improved playgrounds were made. And many more children and families are being served in the program. Accordingly, it would be devastating to every community across the country if Head Start suddenly had to cut back and reduce the size of the program. Numerous jobs would be lost across the country, at-risk families would be dropped from the program with nowhere else to turn, buildings would sit empty, and the gains that have been made would be lost. This country cannot afford for that to happen.

For all of these reasons and more, NHSA hereby requests that this Committee support the President's FY 2011 Budget Proposal for Head Start and other early childhood programs. We have made so much progress in a short period of time. We trust that that this Committee will continue to lead the way in ensuring that the Head Start community can make even more progress. By sustaining the Head Start commitment, together we can move early education and care into a new era for at-risk children and families.

Thank you.

⁶ <http://www.census.gov/hhes/www/poverty/histpov/hstpov20.xls>

YASMINA S. VINCI, MA, MPA

Executive Director

National Head Start Association

A seasoned leader in both executive and policy roles, Yasmina Vinci's professional experience and capabilities have delivered improvements in the lives of children at the national, state, and local levels. Yasmina comes to the National Head Start Association after several years as principal and founder of EDGE Consulting Partners. At EDGE, Yasmina pursued local, national and global projects that utilized the knowledge, experience, and connections of her years in human services and early education, to enhance the capacity of organizations to thrive as competent, strategic entities capable of influencing policy. Yasmina founded EDGE after receiving her Master in Public Administration degree from Harvard's Kennedy School of Government.

Yasmina brings to her new role over ten years of executive director experience at national organizations. As the first Executive Director of the National Association of Child Care Resource & Referral Agencies (NACCRRA), she led NACCRRA's transition from an all-volunteer association of less than 200 child care resource and referral agencies to a powerful national network of 860+ community-based organizations. In this role, she worked with affiliate organizations, other national advocacy and research organizations, the press, federal and state governments, and the US Congress to implement NACCRRA's system-building public policy agenda on early care and education. Under her leadership, NACCRRA organized the national grassroots campaign that was instrumental to securing the funding for child care in the welfare reform legislation.

A deep understanding of child care issues and challenges at the most local level informs Yasmina's experiences. She began her career as the Executive Director of an inner city child care center and, prior to joining NACCRRA, Yasmina was the Manager of Special Projects in the New Jersey Department of Human Services where she managed the Dependent Care Grant, coordinated the development New Jersey's initial plan for the implementation of the Child Care and Development Block Grant, and supervised a number of research, immunization and Head Start-related projects.

Yasmina's board impact has also been substantial and varied. In addition to holding leadership positions on the governing Boards of the National School Age Care Alliance, the Interfaith Council for the Homeless, United Way, YWCA, Alliance for Work Life Progress, ARC and others, she has also served on numerous advisory boards and task forces, and for nine years was Commissioner on the National Head Start Fellowship Commission.

Currently, Yasmina serves on the Governing Board of the Council for Professional Recognition, the Board of the Children's Investment Fund, and numerous Advisory Boards of relevant organizations.

Mr. OBEY. Thank you.
 Next, is it Tunde Eboda? National Association for State Community Services Programs.

WEDNESDAY, MAY 12, 2010.

COMMUNITY SERVICES BLOCK GRANT PROGRAM

WITNESS

TUNDE EBODA, PH.D., CSBG STATE ADMINISTRATOR, DISTRICT OF COLUMBIA, NATIONAL ASSOCIATION FOR STATE COMMUNITY PROGRAMS

Mr. EBODA. Yes, Mr. Chairman. Thank you very much. Chairman Obey, Acting Ranking Member Rehberg, good morning. Members of the Committee, we want to thank you for the opportunity this morning to provide testimony on behalf of the National Association for State Community Services Programs.

We want to thank Congress for the support of the Community Services Block Grant and we look forward to the many opportunities in the future to demonstrate the successes and build upon the successes that we have accomplished in promoting economic stability and mobility for Americans everywhere.

We especially want to thank Chairman Obey for the ardent work that he has done over the week and for being the champion of vulnerable populations. We very much appreciate your service and thank you for it.

Mr. OBEY. Thank you.

Mr. EBODA. I planned today to talk about CSBG outcomes, and we do have a lot of them, but first I want to talk about jobs.

We are the recipient of economic recovery funds, and we are happy to report that this year, so far, we have created and retained or retained a minimum of 8,000 jobs, and have helped approximately 22 percent of Americans in poverty to stay employed and retain economic stability.

The Federal recovery spending data ranks the Community Services Block Grant number 12 out of approximately 200 programs that were reviewed for jobs created and retained. Because of the Recovery Act funds, we have been able to accomplish this many successes.

We stand the risk of losing the Recovery Act funds at the end of 2010. We will be asking and request that a minimum of \$300 million be added to the CSBG funds, which would be approximately 33 percent of what we will be losing as a result of the Recovery Act funds expiring at the end of fiscal year 2010.

What are some of the functions of the state in the Community Services Block Grant Program? We provide, of course, the assurance through the Federal Government and to all stakeholders that we hold community action agencies accountable for the use of Community Services Block Grant funds; we provide the partnerships that is critical to making Community Services Block Grant funds work.

Many other Federal programs are already located within the State. The Temporary Assistance for Needy Families, the Low Income Home Energy Assistance Program, Early Head Start pro-

grams, all combine to make CSBG work through partnerships. We provide the monetary and evaluation that is necessary to assure our stakeholders that we are good stewards of Federal funds.

Additionally, we have the responsibility for providing reports to Congress on an annual basis that demonstrate the successes and how we have overcome challenges that exist within the network.

We are asking also that language in the CSBG statute be retained so that we have the flexibility to recapture funds and redistribute those funds within the CSBG network if agencies do not expend up to 20 percent of their grant going into the next fiscal year.

We have many examples of successes within the CSBG program. We have provided details for the record in the testimony that we have submitted before the Committee today.

We are happy to be here to report on the successes and we have many, many more, and we encourage members to please review the testimony, and we are happy to answer any questions that you may have. Thank you.

[Written statement by Tunde Eboda follows:]

Public Testimony for the Record by the
NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS
Related to Appropriations by the
**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,
HEALTH & HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**
Concerning the
COMMUNITY SERVICES BLOCK GRANT
May 12, 2010
10:00 AM to 12:30 PM

Submitted by: Tunde Eboda, PhD, CSBG State Administrator, District of Columbia.
On Behalf of the
National Association for State Community Services Programs
Phone: (202) 624-5866 Email: jchaffin@nascsp.org

Summary

This testimony is submitted on behalf of The National Association for State Community Services Programs (NASCSPP) on Fiscal Year 2011 appropriations for the Community Services Block Grant (CSBG), located within the Department of Health and Human Services, Administration for Children and Families, Office of Community Services.

This testimony will cover the following topics:

- Overview of the State-administered CSBG with particular focus on contributions to economic recovery efforts and job creation;
- The impact and results of CSBG projects, including examples of innovative programs around the country;
- Explanation of the States' administration of the block grant and recommendations on the best strategies to support them in this role; and
- A summary of CSBG requirements to preserve the progress that was made with Recovery Act funding in job creation and retention.

Chairman Obey, Ranking Member Tiahrt, members of the Committee, thank you for the opportunity to submit this testimony on behalf of the National Association for State Community Services Programs (NASCSPP), the premier national association representing state administrators of the Department of Health and Human Services' Community Services Block Grant (CSBG) and state directors of the Department of Energy's Low-Income Weatherization Assistance Program. I am Tunde Eboda, CSBG Administrator, Community Services Block Grant Program Office, D.C. Department of Human Services.

We thank Congress for its past support of CSBG and look forward to working with you to build on the success of the past year and to promote economic mobility for all Americans in the years ahead. We'd especially like to thank one of this nation's most ardent champions of vulnerable populations, Chairman Obey. Your support in promoting economic opportunity for all Americans reminds us of what this great nation is all about.

I planned to begin today by talking about CSBG's outcomes because there is a lot of good news to report—but first I want to talk about jobs. An economic recovery that doesn't restore employment opportunity to low-income workers so disproportionately hurt by the economic crisis isn't worth the paper it's reported on. I understand fully that resources are scarce, the need is greater than ever, and that this committee faces difficult choices. However, already this year CSBG created 8,000 jobs and provided critical supports that helped 22% of Americans in poverty stay employed or attain greater economic security. Federal recovery spending data ranks the Community Services Block Grant 12th out of approximately 200 federal programs in jobs created or retained. We dare not lose this momentum. To retain the jobs we've created and to maintain our success, we need \$300 million more than our previous year's CSBG allocation. Why are we asking for more? We're not. The total would still be 63% less than we received overall this year.

Experts agree that even as the economy begins to recover, those in the lowest income brackets will still have a hard time finding jobs for years to come. To sustain a recovery, all Americans need to participate in the economy. More than ever we must invest our scarce resources where they'll produce the most results. The funding we request will enable one of the Federal government's most successful economic mobility programs to meet the challenges of the current economic crisis and lay the foundation for a sustained recovery.

This year, with Recovery Act funds and regular CSBG combined, the CSBG Network has nearly \$1.6 billion in available funds. Without Recovery Act funds in Fiscal Year 2011, we will need an additional \$300 million to fund the CSBG so as not to reverse the progress we've made so far. Without this funding, many of the jobs we've created will simply disappear. These jobs not only benefit the workers, but also provide critical support services to local communities and help states better respond to the economic crisis. We cannot afford to reduce this critical program. We need to secure the progress we've made putting Americans back to work.

The States' Role in CSBG

State responsibility and administrative oversight makes the CSBG successful. But States can only be as responsible and effective as they're allowed to be. The Block Grant allows the States

to ensure programs spend funds on time, finish on budget and achieve results. It provides States the flexibility to develop programs and services that meet the needs of their own unique demographics, geography and conditions.

Moreover, State CSBG administrators have a proven track record of effective partnering with other Federal and State programs such as Temporary Assistance to Needy Families, the Low-Income Home Energy Assistance Program and State funded Early Head Start Programs, and of leveraging additional resources to multiply the effectiveness of the CSBG funds.

States monitor their results and manage agencies using the Network's national accountability system because they know they are responsible for producing results and can't afford to fail. States are only mandated by the CSBG Act to monitor CSBG funded agencies once during a three year period, yet most States conduct more intensive oversight than the Act requires.

While the CSBG Act gives States the authority and flexibility they need to hold local agencies accountable and to respond in times of crisis, the success of the CSBG in Recovery Act jobs creation was achieved despite the dangerous lack of critical administrative funding. Any permanent reduction in State Administration allowances will weaken State oversight and reduce accountability at a time when Congress is focused on better investment of limited resources.

FY 2011 appropriations need to uphold the language of the CSBG Act, which allows States to administer the Block Grant effectively. States must be able to use up to 5% of the CSBG for State administrative expenses, such as monitoring, and the remaining funds, after grants are made to eligible entities, for building capacity, innovating programs and ensuring outcomes. Also, income eligibility needs to be maintained at the level established in the Recovery Act, which is 200% of poverty. Finally, States need the ability to recapture and redistribute unobligated funds distributed to an eligible entity if at the end of a fiscal year such funds exceed 20% of the total amount distributed.

For example, times of crisis highlight the terrible results of using appropriations to remove the States' authority. As we saw when Hurricane Katrina swept through the Gulf Coast, and as we're seeing now with the flooding in Tennessee and the oil spill in the Gulf, States can't respond as quickly and effectively as they're capable of doing when they no longer have the flexibility to move resources to where they're needed. FY2011 appropriations need to restore the full authority given the States by the CSBG Act.

About CSBG

The CSBG is worth the additional \$300 million investment because it's the federal government's best resource for identifying and taking to scale innovations which make communities more economically competitive, equitable, and environmentally sustainable. The CSBG network:

- Combines deep local connections with a nationwide accountability structure that manages for outcomes, sustainability and scalability, and replicates successes beyond individual programs.
- Gives States the flexibility to design place-based programs suited to unique local conditions.

- Understands that moving people to economic security involves more than just getting people jobs. Those hardest hit by the economic downturn need comprehensive supports, like education, training and family-supporting wages.
- Leverages additional Federal, State, local and private funding to combine with the Block Grant dollars. In FY 2008, nearly \$598 million from CSBG supported the core activities of the State and local CSBG Network agencies. Every CSBG dollar was matched by \$5.96 from State, local and private resources.
- Has over 45 years of experience integrating a range of initiatives in areas such as education, energy, housing, and transportation.
- Has close connections to local communities and a track record of innovation and adaptability.

CSBG SUCCESSES

In 1994, CSBG created the award winning Results-Oriented Management and Accountability (ROMA) system. ROMA captures the effectiveness of programs using goals and outcomes measures. Here are some of the network's nationally aggregated outcomes achieved by individuals, families and communities as a result of their participation in innovative CSBG programs during FY 2008:

176,000 low-income participants got a job, obtained an increase in employment income or achieved "living wage" **employment** and benefits.

856,000 low-income households achieved an increase in **financial assets** or financial skills.

4.6 million Community opportunities or resources were improved or increased for low-income people.

1.2 million low-income participants obtained supports which reduced or **eliminated barriers to employment**.

3.3 million infants, children, youth, parents and other adults participated in **developmental or enrichment programs** and achieved program goals.

304,000 low-income people mobilized to **participate** in activities that support and promote their own well-being and that of their community.

2.2 million low-income vulnerable individuals maintained an **independent living** situation.

16.1 million low-income individuals and families received **emergency assistance**.

HOW IT WORKS

Here are some examples from some of your own states of how States and local agencies use CSBG funds and CSBG Recovery funds:

Investing in the Future with Education and Skill Training in Minnesota, Maryland and DC

- Community Action Duluth partnered with a local college to provide tuition assistance and supportive services that enabled low-income individuals to get a degree.
- United Communities Against Poverty, Inc. developed the first Green Jobs training and certification program to put low-income Prince George's County residents to work.
- United Planning Organization offered training and apprenticeship opportunities in green building and grounds maintenance to promote job-readiness for this growing field.

Helping People Get and Keep Employment in Wisconsin, Kansas, Montana, and Ohio

- Couleecap, Inc. provided work related resources like tools, special clothing, transportation and even, when necessary, mortgage or rent payments to stabilize housing situations so families could maintain employment.
- Community Action, Inc. of Topeka created on-the job training, work experience and certification in high demand fields such as Commercial Driving and Child Development to increase economic security.
- District XII Human Resource Development Council operated a Summer Employment Program for youth that provided work experience and much-needed income while also beautifying and improving the community.
- Pickaway County Community Action provided on-the-job training in energy conservation and weatherization to move low-income workers into good paying contractor jobs in the community.

Critical Services during the Economic Crisis in Montana, Oklahoma, Wisconsin, and California

- Community Action Partnership of Northwest Montana provides multiple services all in one location, including legal services for housing; domestic violence and credit counseling; and public benefits enrollment.
- INCA Community Services, Inc. serves vulnerable families facing multiple complex barriers to employment. INCA coordinated numerous services to help stabilize these families so they could move beyond addressing basic needs and focus on employment.
- Lakeshore Community Action Program created a financial literacy counseling program that collaborated with a local consumer credit counseling agency to help low-income families make the most of their scarce resources.
- As a leader in their community, Community Action Partnership of Orange County provided technical assistance and capacity building to support other local community organizations in preparing for the increased community needs brought on by the economic crisis.

All of these agencies found that CSBG Recovery Act funds were critical to address the needs in their communities – these needs won't stop abruptly when Recovery Act funding ceases. CSBG is the core funding which holds together a local delivery system that responds effectively and efficiently to the needs of low-wage workers and the broader community. CSBG allows local agencies to develop local funding, private donations and volunteer services and run programs of far greater size and value than the actual CSBG dollars they receive.

For every CSBG dollar they get, CAAs leverage \$5.96 in non-federal resources (state, local, and private) to improve the economic security of low-wage workers and communities.

Since its inception, the CSBG has shown how partnerships between the federal government, states and local agencies benefit citizens in each state. The State CSBG office provides a critical connection to resources, knowledge of state-level and regional issues, partnership experience and a history of outcome measurement; all of which will make economic security and mobility projects highly successful.

WHOM DOES THE CSBG SERVE?

CSBG serves a broad spectrum of low-income persons who aren't reached by other programs. Based on the most recently reported data from FY 2008, CSBG serves:

- More than **3.3 million** families with incomes at or below the Federal Poverty Guideline;
- More than **1.5 million** families in "severe poverty," with incomes below 50% of the Poverty Guideline;
- More than **1.9 million** "working poor" families with wages or unemployment insurance;
- More than **1.3 million** families in which at least one family member was a retired worker;
- More than **425,000 families** receiving TANF—equal to **26%** of all TANF families; and
- More than **1.4 million** families headed by single mothers.

WHY INVEST IN CSBG

The current financial crisis presents a significant opportunity for the nation. We must renew our commitment to invest in our most vulnerable citizens to create an economic recovery for all Americans. The CSBG Network represents our abiding national commitment to create hope and opportunity for all because we are a stronger nation when we do so. The CSBG and CSBG Network are a critical complement to the public sector's efforts to lift low-income Americans and their communities out of poverty and into economic independence.

Investing an additional \$300 million in CSBG for FY 2011 will maintain the economic mobility gains of the past year and allow us to move forward. Leaving behind millions of low-wage workers in a so-called recovery is not morally acceptable, nor in the end does it make for a sustainably strong economy. We can do better. We know what needs to be done. Our nation's future demands it.

Thank you so much, and I am now happy to take your questions.

Biography**Tunde Eboda, Ph.D.**

State CSBG Administrator
Community Services Block Grant Program (CSBG)
District of Columbia

Dr. Eboda's professional expertise is in the collection, analysis and presentation of social statistical data specifically relating to urban and health services research. Additionally, he possesses management experience in public leadership, grants administration, program monitoring and evaluation, municipal bond financing and capital budget formulation. Currently, he is responsible for the management and administration of a \$26 million (2009/2010) Community Services Block Grant program in the District of Columbia. In addition, he is responsible for developing partnerships and evolving innovative relationships between public and private organizations with the goal of moving low-income populations increasingly towards self-sufficiency. Dr. Eboda has been a member of the senior leadership team in the District of Columbia Government for over ten years.

Dr. Eboda has conducted scientific research in the areas of Consumer Banking, Labor Force Participation, Drug Abuse and Health Services Utilization. He has designed and tested evaluation models aimed at assessing causal relationships between explanatory and outcome variables. His original research, "*Results-oriented Health Care for the Hospitalized Elderly Black Male: Predicting Important Outcomes*" was published by UMI: Ann Arbor, Michigan, 2002. In 2007, he was a Brookings Institution Fellow and served as a legislative assistant/advisor on Capitol Hill.

Dr. Eboda has a doctorate in Medical and Urban Sociology from Howard University, Washington, DC and a certificate in Public Leadership from the Brookings Institution, Washington, DC.

Mr. OBEY. Thank you again.

Mr. EBODA. Thank you very much.

Mr. OBEY. Next, Steven Berg, National Alliance to End Homelessness.

WEDNESDAY, MAY 12, 2010.

HOMELESSNESS

WITNESS

STEVEN R. BERG, VICE PRESIDENT FOR PROGRAMS AND POLICY, NATIONAL ALLIANCE TO END HOMELESSNESS

Mr. BERG. Good morning, Mr. Chairman and members of the Subcommittee. The last time we had full national data was early in 2008, and at that point there were two-thirds of a million people homeless in the United States. Now, that is too many people. But that is also significantly fewer people than were homeless even a few years beforehand. We started to make progress on this issue thanks to what communities around the Country are doing to adopt new practices and better approaches.

Homelessness is a problem with a solution, and an important part of that solution is in the jurisdiction of this Subcommittee. My written testimony identifies 11 different items that we believe are key and relevant to continuing to make progress. I want to spend a couple minutes just focusing on three of those that involve some new things.

First of all, SAMHSA has a series of direct grants to nonprofits around the Country to provide services in supportive housing. Supportive housing is deeply subsidized housing, where the rents are subsidized, combined with intensive support services in health treatment that has proven to really work to get people who have been on the streets for many years, who have severe problems of mental health, substance abuse, other kinds of physical problems, to get them off the street, permanently housed, and end their homelessness. That is a model that has directly contributed to thousands of people who used to live on the streets now being housed.

This year there is something in the President's budget that people on this Committee and around the Country have been demanding for many years, which is for an initiative to get HHS and HUD to work more closely together to provide permanent supportive housing. So most of the funding for that is coming from HUD, but there is \$15.8 million in the President's budget to provide supportive services specifically matched up with HUD-funded rental vouchers to provide permanent supportive housing both for homeless people with disabilities and also for homeless families with children. This is a new initiative we think is going to go a long way toward getting those two agencies to work together and to get the people who get their money on the ground to work together. So that is an important item.

Community Health Teams is a grant program that was in the health care reform bill that is ready to go as soon as money is appropriated for it. This would fund primary care providers to coordinate with other providers at the State and local level to provide

services to people in medical homes, which is a term of art, but which applies to permanent supportive housing. So it is another way into this permanent supportive housing problem. We believe an initial allocation of \$20 million for that program, to get that program started and off the ground would be money well spent.

Finally, the third piece has to do with youth homelessness. There are many unaccompanied youth who are homeless in our cities and our rural areas. We do not know as much about that part of the problem, but we do estimate that there is probably 50,000 who are long-term living on the streets, without anyplace to live, without any support from family.

We are working very hard to up the visibility of this issue this year and to really look for better solutions, and we think the Runaway and Homeless Youth Act programs at the Administration for Children and Families are going to be a key part of those solutions.

I would like to close just by saying we have made great progress on this issue over the last few years. The Appropriations Committee has been at the center of that progress by investing in things that work, so on behalf of myself, on behalf of literally hundreds of thousands of people who are going to bed tonight in a modest apartment, who would be sleeping in the back seats of their cars, I want to thank you for the work you have done over the years as a leader on this issue and assure you that we will continue to work on it while you are gone.

[Written statement by Steve Berg follows:]

Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education

by

**The National Alliance to End Homelessness
Steve Berg, Vice President for Programs and Policy**

202-942-8283

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Hearing date: May 12, 2010

The National Alliance to End Homelessness (the Alliance) is a nonpartisan, nonprofit organization committed to preventing and ending homelessness in the United States. With its network of over 10,000 faith-based, nonprofit, and public sector partners, the Alliance is a leading voice on solutions to homelessness and has supported over 250 state and local entities to develop plans to end homelessness. Communities are implementing those plans using proven interventions that couple housing with an appropriate level of supportive services to help people remain permanently housed. With federal and local leadership, the Alliance is committed to ending homelessness once and for all in the United States.

Summary of Appropriations Goals

1. Continue Progress toward Ending Homelessness

Communities across the country are targeting federal, state, and local funds to solution-focused interventions, which helped lead to significant reductions prior to the recession in homelessness among individuals with a disability. In order to continue making progress in the face of today's recession, the Alliance recommends the following:

- Allocate \$120 million to SAMHSA for services for people experiencing homelessness, including \$15.8 million for the Administration's proposed new Homeless Initiative Program.
- Provide \$75 million for the Projects for Assistance in Transition from Homelessness (PATH) program.
- Increase funding for the Runaway and Homeless Youth Act Programs to \$165 million.
- Provide \$3.28 billion for the Community Health Center program, of which \$278 million would go to the Health Care for the Homeless program.
- Fund Education for Homeless Children and Youth services at \$140 million.
- Increase funding for the Homeless Veterans Reintegration Program to \$50 million.
- Provide initial funding of \$20 million for the new Community Health Teams Grant Program, Section 3502 of the Patient Protection and Affordable Care Act.

2. Prevent and End Homelessness by Connecting People to Mainstream Services

The Alliance recommends the following:

- Support the Administration's request to fund the Community Services Block Grant (CSBG) program at \$700 million.
- Appropriate \$60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program.
- Fund the Community Mental Health Block Grant at \$521 million.
- Provide \$2.008 billion for the Substance Abuse Prevention and Treatment Block Grant.

Background

An estimated 671,859 people are homeless on any given night in the United States—248,511 persons in families and 423,348 individuals. Eighteen percent of this group is chronically homeless - they have a disability and have been homeless repeatedly or continuously for 12 months. From 2005 to 2007, local planning efforts, targeted resources, and increases in supportive housing helped account for a 28 percent decline in the number of chronically homeless adults and an 18 percent decline in homelessness among people in families. Due to the recession, however, recent data indicates spikes in homelessness, particularly among families.

To help stave off drastic increases in homelessness, Congress must invest in what we know works. For chronically homeless populations, permanent supportive housing successfully and cost-effectively ends homelessness by coupling housing with intensive supportive services, such as health care, mental health services, addiction treatment, employment training, and case management. Other housing models that combine housing with an appropriate level of services based on client's needs are proving effective for families, individuals, and youth who are experiencing or at risk of homelessness.

We applaud the Federal Government for its leadership in the movement to prevent and end homelessness, and urge Congress to **adequately fund programs that help communities connect people to needed social services and permanent housing. Together, with support at all levels of government, we can finish the job of ending homelessness once and for all.**

Detailed Program Descriptions**Goal 1: Continue Progress toward Ending Homelessness****Support Services for Permanent Supportive Housing Projects**

The Alliance recommends allocating \$120 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment. This should include \$15.8 million for the new Homeless Initiative Program proposed by the Administration, which partners SAMHSA funding, HUD vouchers, and Medicaid to provide the coordinated resources communities need to house people. Years of reliable data and research demonstrate that the most successful solution for chronic homelessness is linking housing to the services people need to maintain their housing. Current SAMHSA investments in homeless programs are highly effective and cost-efficient.

Projects for Assistance in Transition from Homelessness (PATH)

The Alliance recommends that Congress increase PATH funding to \$75 million. PATH programs provide outreach to connect people who are homeless to housing and mainstream services, such as Supplemental Security Income (SSI), Medicaid, and welfare programs. In addition, they provide supportive services such as, rehabilitation, mental health services, substance abuse treatment, case management, residential supervision, which help people move toward self-sufficiency.

Runaway and Homeless Youth Act (RHYA) Programs

The Alliance recommends funding RHYA programs at \$165 million. RHYA programs end episodes of homelessness by helping young people reunify with family or find alternative living arrangements, engaging youth living on the street with Street Outreach Programs, providing emergency shelter and family crisis counseling through the Basic Centers program, or providing supportive housing through Transitional Living Programs. Recently, the Congressional Research Service issued a report complimenting RHYA programs but detailing the gaps in services due to limited funding—only one-tenth of the youth who connect with a RHYA program are able to receive services.

Community Health Centers and Health Care for the Homeless (HCH) Programs

The Alliance recommends \$3.2 billion in the Community Health Center program within Health Resource Services Administration, which would result in \$278 million for the HCH program. People living on the street suffer from health problems resulting from or exacerbated by being homeless, such as hypothermia, frostbite, infections of the respiratory and gastrointestinal systems, tuberculosis, and hypertension. HCH programs prevent these conditions from being fatal and provide services that are linked to affordable housing to help people remain housed and move toward self-sufficiency.

Education for Homeless Children and Youth (EHCY)

The Alliance recommends funding EHCY at \$140 million. The mission of the EHCY program is to ensure that children can continue to attend school while they are homeless. In addition EHCY, within the Department of Education's Office of Elementary and Secondary Education, prevents and ends episodes of homelessness by establishing school liaisons who connect household to homelessness services and prevention assistance in the community. Current funding levels leave more than 300,000 identified homeless children and youth without direct services in 2007-2008.

Homeless Veterans Reintegration Program (HVRP)

The Alliance recommends that Congress increase HVRP funding to \$50 million. Not having a stable income is one of the biggest barriers to permanent housing. HVRP, within the Department of Labor's Veterans Employment and Training Service (VETS), provides competitive grants to community-based, faith-based, and public organizations to offer employment services, job placement, and supportive services to homeless veterans. It is estimated that this program only reaches about two percent of the overall homeless veteran population. An appropriation at the authorized level of \$50 million would enable HVRP grantees to reach approximately 19,866 homeless veterans.

Community Health Teams Grant Program (CHT)

The Alliance recommends that Congress provide \$20 million for an initial round of CHT grants. This new program, created by Section 3502 of the Patient Protection and Affordable Care Act, will provide grant funds to states and tribes to fund Community Health Teams. These teams of primary care providers and other state- and community-based resources will support people living in patient-centered medical homes, an ideal model for homeless people with severe disabilities living in permanent supportive housing.

Goal 2: Prevent and End Homelessness by Connecting People to Mainstream Services

Community Services Block Grant (CSBG)

The Alliance recommends supporting the Administration's request of \$700 million for CSBG in FY 2011. CSBG funds are used to connect low-income people to services which help them move into or maintain permanent housing. Community Action Agencies (CAAs), which are the primary local recipients of CSBG funding, are directly involved in local efforts to end homelessness, and this funding will improve their capacity and level of coverage.

Foster Youth Education and Training Vouchers

The Alliance recommends that Congress appropriate \$60 million in education and training vouchers for youth exiting foster care under the Safe and Stable Families Program. Research of youth in transition from foster care has shown that over a quarter will experience homelessness within their first few years of adulthood. The Education and Training Voucher Program protects these youth by connecting them with housing, education, and vocational opportunities to stabilize youth, prevent economic crisis, and prevent future homelessness. Students may receive up to \$5000 a year for college or vocational training education, and these funds may be used for tuition, books, housing, or other qualified living expenses.

Community Mental Health Block Grant

The Alliance recommends that Congress appropriate \$521 million for the Community Mental Health Performance Partnership Block Grant. Approximately half of people experiencing homelessness suffer from mental health issues. Additional mental health funds will give states the resources they need to improve their mental health system and better serve people who are homeless and living with a mental illness. The Mental Health Block Grant provides flexible funding to states for mental health services, including services linked to permanent supportive housing for homeless people.

Substance Abuse Prevention and Treatment (SAPT) Block Grant

The Alliance recommends that Congress appropriate \$2.008 billion for the SAPT Block Grant. Studies have shown that half of all people experiencing homelessness have a diagnosable substance use disorder. States need more resources to implement proven treatment strategies coupled with affordable housing to help some homeless populations, especially chronically homeless populations, stably housed. The SAPT Block Grant is the primary source of federal funding for substance abuse treatment and prevention for many low-income individuals, including those experiencing homelessness.

Conclusion

Homelessness is not inevitable. As communities implement plans to end homelessness, they are struggling to find funding for the services that homeless and formerly homeless clients need to maintain housing. The federal investments in mental health services, substance abuse treatment, employment training, youth housing, veterans' services, and case management discussed above will help communities create permanent housing solutions and change social systems to end homelessness in America.

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Education:

Harvard Law School, J.D. 1982. Honors graduate, Legal Services Institute full-year clinical program, Prison Legal Assistance Project.

Lewis and Clark College, B.A. 1978. Political Science major, magna cum laude, overseas study in India.

Experience:

Vice President for Programs and Policy, National Alliance to End Homelessness, October 1997 to present (previously Director of Programs).

Senior Policy Analyst, Center on Budget and Policy Priorities, September 1996 to September 1997.

Staff Attorney, Connecticut Legal Services, September 1990 to August 1996 (Norwalk and Bridgeport Offices).

Executive Director, Legal Aid Foundation of Santa Barbara County, May 1988 to August 1990

Clinical Instructor, Santa Barbara College of Law, January 1988 to August 1990.

Staff Attorney, Legal Aid Foundation of Santa Barbara County, August 1987 to May 1988.

Trainer, Benchmark Institute, October 1986 to present.

Staff Attorney, Contra Costa Legal Services Foundation, September 1983 to August 1987.

Volunteer Attorney, California Rural Legal Assistance, November 1982 to September 1983.

Legal Intern, Common Cause, Summer 1981.

Mr. OBEY. Thank you much.

Mr. BERG. Thank you.

Mr. OBEY. Next, Kevin Martone, National Association of State Mental Health Program Directors.

WEDNESDAY, MAY 12, 2010.

MENTAL HEALTH BLOCK GRANT

WITNESS

KEVIN MARTONE, COMMISSIONER, NEW JERSEY DEPARTMENT OF HUMAN SERVICES, DIVISION OF MENTAL HEALTH SERVICES, NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

Mr. MARTONE. Mr. Chairman, members of the Subcommittee, I want to thank you for the opportunity to appear before you today. My full-time job, I am New Jersey's Mental Health Commissioner. Today, I am here to reflect the views of the National Association of State Mental Health Program Directors, NASMHPD, which represent the public mental health authorities in the 50 States, as well as the District of Columbia and the territories. Permit me to briefly summarize the situation we confront. The larger State fiscal crisis is having a severe impact on public mental health systems across the United States and is certainly being felt in New Jersey. According to February 2010 data collected by NASMHPD's Research Institute, between fiscal year 2009 and fiscal year 2011, States have been forced to cut mental health agency budgets by a combined total of \$1.82 billion. That estimate reflects reporting from 45 States.

Mr. Chairman, to put this in historical context, that number probably represents the largest total funding reduction to public center mental health services in nearly 50 years. The effect of these shortfalls on America's mental health safety net, as well as the consumers it serves, can only be described as devastating. Some States have been forced to make cuts equaling 20 percent of their total mental health spending. In the worst hit States, reductions approaching 40 percent are being contemplated or have already been implemented.

As an illustration, in Ohio, the combined State mental health cut over the last three fiscal years total over \$191 million. The total percentage reduction equals 36 percent across the board.

To date, the programs hardest hit are indigent care initiatives providing mental health services to low-income people and uninsured adults, many of whom recently lost health insurance coverage in this recession. Let me take a moment to give you some specific examples of what these cuts mean in our communities.

In Illinois, Governor Quinn is being forced to contemplate a \$90 million funding cut to Illinois' Division of Mental Health Community Services. Once Medicaid reimbursements reductions are included, the proposed State cut would result in a 40 percent reduction in community-based mental health services statewide. It is estimated that more than 70,000 low-income persons, including over 4200 children, will lose access to mental health care.

In Kansas, 9 of the State's 27 community mental health centers are in the red and may close. Most serve rural health professional shortage areas. Furthermore, it is astonishing to note that Kansas is actively contemplating a complete freeze on all new admissions to the State's public psychiatric hospitals for up to a full year.

In New Jersey, consistent with the United States Supreme Court's Olmstead decision, and with Governor Christie's support, we are reducing the number of State psychiatric hospitals and serving more people with severe mental illnesses in the community, closer to family and friends. In fiscal year 2011, our Division will close Hagedorn Psychiatric Hospital, producing a projected savings of \$9 million.

Yet, at the same time, the budget crisis has forced us to reduce community contracts and my division was required to make targeted cuts to partial care, case management, and jail diversion programs. This situation greatly contemplates our ability to close Hagedorn. Moreover, in all candor, what keeps me up at night is that fiscal year 2012 does not look much better than 2011.

Let me end my testimony by making two larger points. First, State mental health agencies nationwide are caught in a policy vice. We are losing State and county revenues, while at the same time the recession is producing a huge spike in the number of people coming to us for mental health care. Twenty States are reporting increased demand for both outpatient services, as well as acute care hospital services. In Rhode Island, for instance, community mental health service centers served nearly 22,000 people with mental illnesses last year, one of the highest totals in its State history.

Second, although Federal Medicaid FMAP increases approved in ARRA have helped temporarily avert even deeper cuts, they have not shielded the public mental health system from the worst funding reductions in nearly five decades. In addition, the new health care reform law will not begin providing health insurance to many indigent persons for several years, and many of the intensive rehabilitative services these individuals require will not be covered by the new insurance exchanges or Medicaid.

In March 2010, Representatives Tonko and Napolitano, along with 35 other members of Congress, wrote to this Subcommittee requesting a \$100 million increase for SAMHSA's Community Mental Health Services Block Grant, resulting in a total funding level of \$520 million. Both NASMHPD and the New Jersey Division of Mental Health Services strongly support this request.

Yes, I acknowledge that the Tonko and Napolitano request is without precedent, but the scale of the fiscal crisis we confront is also unprecedented. The hard fact is that Mental Health Block Grant is the only program available to help public mental health authorities recover State and county service dollars lost during the current fiscal crisis.

I welcome any questions you may have.

[Written statement by Kevin Martone follows:]



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**TESTIMONY OF
MR. KEVIN MARTONE
DEPUTY COMMISSIONER
NEW JERSEY DEPARTMENT OF HUMAN SERVICES
DIVISION OF MENTAL HEALTH SERVICES**

**REPRESENTING THE
NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM
DIRECTORS**

**PRESENTING BEFORE A MAY 12, 2010 HOUSE LABOR/HEALTH AND
HUMAN SERVICES APPROPRIATIONS SUBCOMMITTEE HEARING ON
SAMSHA'S COMMUNITY MENTAL HEALTH SERVICES BLOCK GRANT**

Mr. Chairman, and members of the subcommittee, on behalf of the New Jersey Division of Mental Health Services, I want to thank you for the opportunity to appear before you this morning. This testimony reflects the views of the National Association of State Mental Health Program Directors, which represents public mental health authorities in the fifty states as well as the District of Columbia and the territories.

Permit me to briefly summarize the situation we confront: the larger state fiscal crisis is having a severe impact on public mental health systems across the United States and is certainly being felt in New Jersey. According to February 2010 data collected by the NASMHPD Research Institute – between FY 2009 and FY 2011 – states have been forced to cut mental health agency budgets by a combined total of \$1.82 billion. That estimate reflects reporting from 45 states. If you include Illinois and California, the combined cut surely tops \$2 billion. Mr. Chairman, to put this in historical context, that number probably represents the largest total funding reduction to public sector mental health services in 40 or 50 years.

The effect of these shortfalls on America's mental health safety net as well as the consumers it serves can only be described as devastating. Some states have been forced to make cuts equaling 20% of their total mental health spending. In the worst hit states, reductions approaching 40% are being contemplated or have already been implemented.

As an illustration, in Ohio, the combined state mental health cut over the last three fiscal years totaled over \$191 million. The total percentage reduction equals 36.2% across the board. It is important to note that these cuts are not reductions from projected future baseline spending. Rather, at the state level, these are year-over-year...dollar-for-dollar reductions.

To date, the programs hardest hit are indigent care initiatives providing mental health services to low income people and uninsured adults – many of whom recently lost health insurance coverage in the recession. Let me take a moment to give you some specific examples of what these cuts mean on the ground in terms of impact on actual services:

- In Illinois, Gov. Quinn is being forced to contemplate a \$90 million funding cut to Illinois Division of Mental Health community services contracts. Once Medicaid reimbursement reductions are included, the proposed state cut would result in a 40% reduction in community-based mental health services statewide. It's estimated that more than 70,000 low income persons – including over 4,200 children – will lose access to mental health care.
- In Kansas, nine of the states' 27 Community Mental Health Centers are in the red and may close. Most serve rural health professional shortage areas. Furthermore, it is astonishing to note that Kansas is actively contemplating a complete freeze on all new admissions to the state's public psychiatric hospitals for up to a full year.

- In Mississippi, Gov. Barbour has proposed closing six crisis centers and two inpatient psychiatric hospitals. As many as 2,200 persons with serious mental illnesses will lose access to services and 627 state employees will be laid off.

In New Jersey, consistent with the US Supreme Court's Olmstead decision and with Gov. Christie's support, we are reducing the number of state psychiatric hospitals and serving more people with severe mental illnesses in the community closer to family and friends. Our Division will close Hagedorn Psychiatric Hospital, which is a 275 bed inpatient hospital in Hunterdon County by June, 2011 producing a projected savings of \$9 million in FY 2011. At the same time, the budget crisis has forced us to reduce community contracts and my division was required to make targeted cuts to partial care, case management and jail diversion programs. This situation greatly complicates our ability to close Hagedorn. Moreover, in all candor, what keeps me up at night is that – in terms of the DMHS budget -- FY 2012 does not look much better than FY 2011.

Let me end my testimony by making two larger points. First, state mental health agencies nationwide are caught in a policy vice. We are losing state and county revenues while, at the same time, the recession is producing a huge spike in the number of people coming to us for mental health care. According to NASMHPD Research Institute data, 20 states are reporting increased demand for both outpatient clinic services as well as acute care hospital services. In Rhode Island, for instance, Community Mental Health Centers served over 21,800 people with mental illnesses last year – one of the highest totals in state history.

Second, although federal Medicaid FMAP increases approved in ARRA have helped to avert even deeper cuts, they have not shielded the public mental health system from the worst funding reductions in four or five decades. In addition, the new health care reform law will not begin providing health insurance to many indigent persons for several years and many of the intensive rehabilitative services these individuals require will not be covered by the new insurance exchanges or Medicaid.

In March 2010, Rep. Paul Tonko and Rep. Grace Napolitano – along with 35 other members of Congress – wrote to this subcommittee requesting a \$100 million increase for SAMHSA's Community Mental Health Services Block Grant resulting in a total funding level of \$521 million for the program. Both NASMHPD and the New Jersey Division of Mental Health Services strongly endorse this request.

Yes, I acknowledge that the Tonko/Napolitano request is without recent precedent, but the scale of the fiscal crisis we confront is also unprecedented. The hard fact is that the Mental Health Block Grant is the only program available to help public mental health authorities recover state and county service dollars lost during the current fiscal crisis.

Again, thank you for the opportunity to testify. I am happy to answer any questions you may have.

Kevin M. Martone

Summary of Qualifications

- Executive level experience in state government and non-profit human services field with expertise in public mental health administration.
- Respected leader at the national, state and local level in behavioral health policy.
- Proven abilities in management of large reform efforts and multi-billion dollar budgets.
- Demonstrated ability to work collaboratively with executive, legislative and judicial branches of government, providers, advocacy groups and organized labor
- Strong clinical background as foundation for diverse management skills.
- Excellent public speaking ability.
- Extensive experience with print, television and radio press

Professional Experience

| | |
|--|-------------------|
| NEW JERSEY DEPARTMENT OF HUMAN SERVICES – Trenton, NJ | 8/2005 to Present |
| Deputy Commissioner | 1/2009 to Present |

Executive oversight of the statewide Divisions of Mental Health, Addictions, Deaf/Hard of Hearing, the Commission for the Blind and Visually Impaired and the DHS Office of Emergency Management; combined budget in excess of \$1.5 billion. Extensive interface and decision-making with all departmental functions, including Medicaid and welfare. Work closely with DHS Commissioner on establishing and executing statewide policy in all human service issues. Delegated title of Acting Commissioner for DHS in Commissioner's absence; DHS budget totals \$8+ billion. Regular contact with Governor's Office, legislature and other state, federal and county government. Represent department and Commissioner in multiple forums, including with organized labor. Extensive interaction with print, television and radio press.

Current Initiatives:

- Policy development for healthcare reform and health information technology, especially as it pertains to mental health and addictions.
- On behalf of Department of Human Services, negotiated successful settlement agreement pertaining to *Olmstead* litigation. Monitor implementation of *Olmstead Plan* at Division of Mental Health Services following settlement agreement.
- Integrate department-wide supportive housing activity, including homeless and criminal justice involved diversion and re-entry housing, throughout all levels of government.
- Manage US Department of Justice CRIPA investigation on behalf of Department. Liaison with State Attorney General's office, Governor's Office, press, stakeholders.
- Interface with US Department of Health and Human Services on various issues impacting DHS.
- Coordinator for DHS H1N1 influenza preparedness and response for 20,000 individuals.
- Managed emergency repatriation of Haiti evacuees at McGuire Air Force Base in coordination with military and federal agencies.

Assistant Commissioner, Division of Mental Health Services

8/2005 to 1/2009

Gubernatorial appointment as the State mental health commissioner. Responsible for executive oversight of the fourth largest public mental health system budget in the United States. Advise the Governor, DHS Commissioner, and Legislature on all policy, fiscal and operational issues related to mental health. Oversee five state-operated psychiatric hospitals (one forensic) that serve 3,000 individuals annually and employ 6,000. Extensive experience with media, public speaking, and stakeholder and community relations.

Selected Accomplishments:

- Led systemic transformation toward statewide model built upon wellness, recovery and public health
- Designed, organized and implemented *Olmstead Plan* for State that reduced state hospital census by 350 patients in three years, while negotiating *Olmstead litigation* on behalf of State.
- Increased access to services for people with mental illness through \$80 million expansion of community system
- Facilitated the development of over 750 affordable, supportive housing units in less than four years for people with mental illness and addictions
- Instituted multiple reforms in the state psychiatric hospital system, including the delivery of evidence-based treatment, staff training, tobacco cessation
- Released state hospital incident dashboard report on DHS web-site, first of its kind in the United States
- Prompted Legislature to pass a tobacco cessation law in the state-operated psychiatric hospitals
- Oversaw construction and opening of new \$200 million state-of-the-art psychiatric hospital on behalf of DHS
- Administrative oversight of the State's sexually violent predator treatment program
- Oversight of state disaster mental health response; facilitated first credentialing program of its kind in the United States to credential state's crisis mental health response workforce
- Implemented performance-based contracting for third party, community-based contracts
- Testified regularly at various legislative committees

**NATIONAL ASSOCIATION OF STATE MENTAL HEALTH
PROGRAM DIRECTORS (NASMHPD) - Alexandria, Virginia
Board of Directors**

7/2007 to Present

Elected to second term to the Board of Directors by national membership as the Northeast Regional Representative to NASMHPD. NASMHPD is the national association that represents 55 state and territorial mental health commissioners in the United States. Participate in all Board decisions in developing and influencing national public mental health policy, including congressional, Medicaid, healthcare reform, and criminal justice strategy. Meet with US Substance Abuse and Mental Health Services Administration (SAMHSA) officials and members of Congress on mental health policy matters.

**Mental Health/Medicaid Directors National
Technical Assistance Group (TAG)
Co-Chairperson**

2/2009 to Present

Invited by the National Association of State Medicaid Directors to represent NASMHPD on this technical assistance workgroup. TAG provides technical assistance to state Medicaid directors on mental health issues, healthcare reform, as well as to the federal Centers for Medicare and Medicaid Services (CMS) and SAMHSA.

US DEPARTMENT OF HEALTH AND HUMAN SERVICES 6/2009 to Present
Agency for Health Care Quality and Research (AHRQ) - Rockville, Md.
Expert Research Panel

Invited to serve on an expert research panel on congressionally mandated initiative to develop quality indicators for home and community-based services (HCBS) offered under State Medicaid Title XIX Programs. Indicators will be implemented in data, software, and documentation tools to be used by state and federal agencies. The researcher panel assists the project team in assessing (a) whether the measures are well defined and precisely specified, (b) that the appropriate populations at risk are addressed, (c) that the measure outcomes reflect access to high quality care and support, and (d) that clinically necessary measure exclusions or sub-population stratifications necessary for appropriate inferences or examination of disparities are identified. Work began in October 2009.

RUTGERS UNIVERSITY 1/2010 - Present
Graduate School of Social Work - New Brunswick, NJ
Part-time Lecturer

Teach Social Work Practice II macro level course to graduate students.

NEW JERSEY GOVERNOR'S TASK FORCE ON MENTAL HEALTH (TFMH) 11/2004 to 12/2005

Gubernatorial appointment to evaluate New Jersey's public mental health system and make recommendations for reform. TFMH process involved several public hearings and extensive stakeholder involvement. Served as Chair for the Housing Advisory Sub-committee of the TFMH which made key recommendations to address housing needs, including the creation of a \$200 million Special Needs Housing Trust Fund. Authored the Housing Report, and co-authored the Final Report.

ADVANCE HOUSING, INC. - Hackensack, New Jersey 2/1997 to 7/2005
President and CEO 9/1999 to 7/2005

Chief executive officer of corporation that develops and operates supportive housing services to over 100 people with mental illness throughout New Jersey's northern region. Ensured that quality, comprehensive services are provided to recipients. Directed all clinical program design and implementation. Developed housing through federal, state, local and private lending resources. Coordinated all financial activities with controller, including accounting and auditing. Secured additional streams of revenue through various activities, including fundraising and grant writing. Ensured compliance with all regulatory bodies. Represented and marketed the agency in various forums, including committees, municipalities, and fundraising activities. Guided clinical and administrative training activities to ensure a competent workforce. Provided training, education and supervision to clinical, fiscal, property management and support managers. Updated Board of Trustees on a regular basis regarding agency activities and status.

Clinical Specialist 2/1997 to 9/1999

Founding member of organization created to meet supportive housing needs of people with mental illness and co-occurring substance use disorders, including those with forensic backgrounds. Supervised the daily operations of the agency, including clinical and property development/management. Duties range from case management services to individual and group therapy. Conducted admissions evaluations, ongoing service provision, crisis intervention, and discharge planning. Extensive experience working with state/local hospital treatment teams and patients. Managed caseload and facilitated family support groups for agency.

Managed program budget and various contracts with Executive Director. Represented agency in a variety of forums, including State and community functions. Effectively interfaced with state and local government, multiple service providers, landlords, and consumers and family members. Chaired Quality Improvement and Utilization Review Committees. Wrote several sections of the agency's policy and procedure manual, including Consumer Rights and Ethical Concerns, Management Information,

Improving Organizational Performance and Risk Management. Participated in the development of the Personal Care program, and implemented its billing procedures. Lead grant writer for federal and state funding initiatives.

SUPPORTIVE HOUSING ASSOCIATION 2002 to 2004
OF NEW JERSEY (SHA) - Cranford, NJ
Vice President, Board of Trustees

Elected by statewide membership to Board of Trustees and to position as Vice President. Advanced supportive housing policy in New Jersey at the State, county and local level. Provided statewide training and education for member organizations on supportive housing. Represented SHA in various forums with governmental agencies and elected officials.

COMPREHENSIVE BEHAVIORAL HEALTH CARE - Hackensack, NJ 6/1993 to 2/1997
Partial Care Specialist 1995 to 1997

Promotion from Mental Health Worker position; supervisory role in partial care program for seriously mentally ill adults. Participated in treatment team meetings, interviewed and trained new staff, and coordinated staff trainings. Facilitated crisis interventions for the department; interacted with local police and courts as needed. Developed a comprehensive substance awareness program targeted toward co-occurring disorders. Demonstrated advanced knowledge in the area of mental illness and agency policies and procedures. Active member of the agency's Policy and Procedures Revision and Utilization Review Committees and Municipal Crisis Response Team. Selected to "Team CompCare" in 1996 for outstanding job performance.

Mental Health Worker 6/1993 to 1995

Responsible for providing individual case management and group counseling services, including psychiatric rehabilitation, supportive counseling, crisis intervention and advocacy, to seriously mentally ill adults, frequently with co-occurring substance use disorders, in a partial care milieu. Regular service coordination with state/local psychiatric hospitals and residential providers. Active member of the agency's Municipal Crisis Response Team and the Utilization Review Committee.

Education/Licensure

LICENSED SOCIAL WORKER, NJ STATE BOARD OF SOCIAL WORK EXAMINERS

RUTGERS UNIVERSITY - Newark, NJ
Master of Social Work, 5/1998

KEAN COLLEGE - Union, NJ
Bachelor of Psychology, 5/1993

Professional Committees & Task Forces

Selected committee participation includes the following:

- Governor's Interagency Council on Prevention of Homelessness (2009)
- Chair, Department of Human Services Housing Advisory Committee (2009)
- Governor's Police Suicide Task Force (2008)
- Governor's Task Force on Mental Health (2004-2005); Chair, Housing Advisory Committee
- Chair, Sussex County Professional Advisory Committee (PAC) (2005)
- NJ Association of Mental Health Agencies Public Policy Committee (2003-2005)
- Sussex County Comprehensive Emergency Access System (CEAS) committee (2003-2004)
- Member Bergen County Professional Advisory Committee (1999-2004)
- DMHS Housing Workgroup and Medicaid Planning Workgroup (2003)
- Various consulting work with service providers.
- Bergen County Homeless Service Providers Committee
- Bergen County Residential Task Force

Lectures, Presentations, Papers

Selected speaking engagements include the following:

- National Association of State Mental Health Program Directors (NASMHPD), St. Louis, MO. *Presentation to state mental health commissioners on economic impact of recession on public mental health system budgets.* July 2009
- U.S. Substance Abuse Mental Health Services Administration (SAMHSA), Washington, D.C. *Thinking Strategically When the Alligators Are At Your Door.* A presentation to mental health planners from all 50 states and territories on policy and budget planning/implications during the recession. June 2009
- New Jersey League of Municipalities Housing Summit, *Supportive Housing Across Disability Lines In Difficult Budget Times.* A presentation to local government officials, housing developers and service providers on relevance and cost effectiveness of supportive housing. May 6, 2009.
- Foothold Technology, New York University, New York City. *Why Your Data Matters to Your Funders.* A presentation to service providers on the importance of technology to policy makers. June 2009
- National Alliance for Mental Illness – NJ, Annual Conference, *Challenges and Choices.* A presentation on managing budget reductions during national recession. June 2009
- Bergen County Advocacy Breakfast, Presentation to county and state elected officials on mental health policy and healthcare reform challenges confronting New Jersey. May 2009
- Collaborative Support Programs of New Jersey Wellness Conference, *Resiliency, Every Day.* A presentation on the importance of resiliency during economic recession. March 2009

- New Jersey Prevention Network, Opening remarks to NJ substance abuse prevention network on importance of prevention during recession. Atlantic City, New Jersey, March 2009
- New Jersey Psychiatric Rehabilitation Association, *The Psychology of Wellness, Recovery and the Economy*. A presentation on achieving policy reform during economic recession. November 2008
- NASMHPD, National Technical Assistance Center for Mental Health, National Transformation Leadership Institute, *Acute Care Transformation in New Jersey*. A presentation on a policy shift from acute care toward preventative and recovery oriented services. Philadelphia, PA October 2008
- National Alliance for Mental Illness – NJ, Annual Conference, *Putting the Pieces Together*. A presentation on public mental health transformation across systems. June 2008
- New Jersey Coalition of Mental Health Consumer Organizations, *Sowing Seeds Yields Big Results*. A presentation to statewide consumer organization on building system transformation. February 9, 2008
- New Jersey Coalition of Mental Health Consumer Organizations, *New Jersey's Commitment to Consumers as Providers in the Workforce*. November 29, 2007
- Annual Governor's Housing and Community Development Conference, Atlantic City, NJ, Multiple presentations on supportive housing development and services. 2004, 2005, 2006, 2007, 2009.
- New Jersey Self-help Center Leadership, *Self-help Centers: A Viable Community Resource*. A presentation to state self-help leaders on the relevance and viability of self-help centers in public mental health. June 4, 2007
- New Jersey Association of Mental Health Agencies (NJAMHA), *Wellness and Recovery: A Division Policy, A Partnership for Change*. A presentation to statewide trade association regarding importance of coalition building during system transformation. April 2007
- New Jersey Annual State League of Municipalities Conference, 2007
- New Jersey conference on Cultural Diversity in Mental Health, 2007 & 2008
- New Jersey Psychiatric Rehabilitation Association, *New Jersey's Transformation: Taking ownership*. A presentation on stakeholder responsibility in public mental health system transformation. November 2006
- NJMAHA conference panelist and workshop presenter 2005
- New Jersey 7th annual PACT conference April 2005
- NJ Office of Attorney General disability law conference April 2005

- *Law and Disability Issues conference March 2005*
- Columbia University Annual Schizophrenia Conference, *Supportive Housing for the Mentally Ill: Making it Work*. A presentation to professionals, academia, and family members regarding the effectiveness of supportive housing for the seriously mentally ill. 2001
- Supportive Housing Association of New Jersey Annual Conference 2003, 2004, 2009
- Essex County Annual Mental Health Legislative Breakfast 2002, 2003, 2007
- NJAMHA conference panelist and workshop presenter 2005
- Passaic County Advocates for Supportive Housing conference 2004
- Sussex County Partners in Housing conference 2004

Recent Awards

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| <p>New Jersey Coalition of Mental Health Consumer Organizations (COMHCO) <i>Community Recognition Award, January 24, 2009</i></p> <p>Northwest Essex Community Healthcare Network, October 16, 2008</p> <p>National Alliance for the Mentally Ill NJ (NAMI NJ), <i>The Governor Richard J Codey Mental Health Champion Award, June 2, 2007</i></p> <p>Mental Health Association of Morris County, June 4, 2007</p> <p>National Resource Center for Hispanic Mental Health, <i>Outstanding Leaders for a Brighter Future for Hispanics, March 22, 2007</i></p> <p>United States Senator Robert Menendez Recognition, March 22, 2007</p> <p>Mental Health Association of NJ, 2007</p> <p>Collaborative Support Programs of NJ, Institute for Wellness and Recovery, <i>Leadership Award, March 8, 2007</i></p> <p>New Jersey Association of Mental Health Agencies, <i>Housing Advocacy Award, September 9, 2005</i></p> |
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References Available on Request

Mr. OBEY. [Remarks made off microphone.]
Next, Michael J. Fitzpatrick, National Alliance on Mental Illness.

WEDNESDAY, MAY 12, 2010.

**SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES
ADMINISTRATION**

WITNESS

MICHAEL J. FITZPATRICK, EXECUTIVE DIRECTOR, NATIONAL ALLIANCE ON MENTAL ILLNESS

Mr. FITZPATRICK. Chairman Obey and members of the Subcommittee, I am Mike Fitzpatrick. I am the Executive Director of the National Alliance on Mental Illness. I am pleased today to offer NAMI's views on the Subcommittee's upcoming fiscal year 2011 bill. NAMI is the Nation's largest grassroots advocacy organization representing persons with serious mental illness and their families.

I first want to thank the Subcommittee for a long bipartisan history of supporting funding for research and services for people with serious mental illness. As you know, the cost of mental illness to our Nation is enormous.

I want to summarize NAMI's statement to you by making three major points.

The investments in research at the National Institute of Mental Health are critical for our Nation. NAMI joins the ad hoc group on medical research recommending \$36 billion in overall funding for the National Institutes of Health, representing a 12 percent increase.

NAMI also recommends a corresponding 12 percent increase of \$1.7 billion for the National Institute of Mental Health. This increase will enable NIMH to continue supporting two critical initiatives that were started using stimulus monies.

The first is RAISE, Recovery After an Initial Schizophrenia Episode. This is the first ever large-scale trial supporting early and aggressive treatment, integrating a variety of different therapies to reduce symptoms and prevent the gradual deterioration or functioning that is characteristic of schizophrenia.

The second project is STARRS, which is the Study to Assess Risk and Resilience in Service Members, a joint Army and National Institute of Mental Health study of suicide and mental health among military personnel.

Additionally, this 12 percent increase will allow the National Institute of Mental Health to continue supporting other important research initiatives to find better treatments and ultimately a cure for disabling illnesses.

Our second point is this Subcommittee must address, as you just heard from the Commissioner of New Jersey and from NASMHPD, the current crisis in funding of the public mental health system.

Mr. Chairman, as our Nation continues to struggle with this current economic downturn and States continue to struggle with diminished revenue, we see a crisis in America's mental health system that we have not seen in our tenure at NAMI over the past 31 years. The system is literally collapsing in front of us. We echo and have the same numbers that NASMHPD has, the cuts of near-

ly \$1.8 billion since 2009. We see cuts in States totaling as much as 20 percent and more. Looking at the budget numbers in State budgets for the next two or three years, we see this picture not changing through 2011, 2012.

This has led to the elimination of State hospital beds, the closure of important, essential mental health services, and really has left the burden in communities falling on jails, homeless shelters, and emergency rooms as really the backbone of the mental health systems. This is tragic and really unacceptable.

To help fill these gaps left by these ill-conceived cuts, NAMI strongly recommends a \$100 million increase to the Mental Health Block Grant for fiscal year 2011. Funding for the Block Grant has been frozen at its current level of \$420 million since fiscal year 2000. An increase is long overdue. While this will not make up for the cuts to services on the State side, this is an important step that Congress must take to assist our most vulnerable citizens.

NAMI also supports targeted increases in the President's budget for the Center for Mental Health Services, including the PATH program, the Children's Mental Health program, Suicide Prevention Programs under the Garrett Lee Smith Memorial Act, and homeless programs at SAMHSA.

And third, and finally, for fiscal year 2011, the Subcommittee should continue the progress it has made in recent history in addressing the Social Security claims and appeals backlog. Mr. Chairman, people with mental illness and other severe disabilities have been bearing the brunt of the backlog crisis for disability claims at Social Security. Behind the numbers are individuals whose lives have unraveled because of this backlog.

We applaud the work the Subcommittee has done in recent history to boost funding to the Social Security Administration. We would ask you just to please continue this progress by supporting the President's funding recommendations regarding the Social Security Administration.

Thank you for the opportunity to speak to you today.

[Written statement by Michael J. Fitzpatrick follows:]



**STATEMENT OF MICHAEL J. FITZPATRICK
EXECUTIVE DIRECTOR, NATIONAL ALLIANCE
ON MENTAL ILLNESS**

**TO THE LABOR-HHS-EDUCATION
SUBCOMMITTEE
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES**

**REGARDING FY 2011 FUNDING FOR THE
NATIONAL INSTITUTE OF MENTAL HEALTH
(NIMH), THE SUBSTANCE ABUSE AND MENTAL
HEALTH SERVICES ADMINISTRATION (SAMHSA)
AND THE SOCIAL SECURITY ADMINISTRATION
(SSA)**

May 12, 2010

Chairman Obey and members of the Subcommittee, I am Mike Fitzpatrick, Executive Director of NAMI (the National Alliance on Mental Illness). I am pleased today to offer NAMI's views on the Subcommittee's upcoming FY 2011 bill. NAMI is the nation's largest grassroots advocacy organization representing persons living with serious mental illnesses and their families. Through our 1,100 affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with serious mental illnesses such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and major mental illnesses affecting children.

The cost of mental illness to our nation is enormous. It is estimated that the direct and indirect cost of untreated mental illness to our nation exceeds \$80 billion annually. However, these direct and indirect costs do not measure the substantial and growing burden that is imposed on "default" systems that are too often responsible for serving children and adults with mental illness who lack access to treatment. These costs fall most heavily on the criminal justice and corrections systems, emergency rooms, schools, families and homeless shelters. Moreover, these costs are not only financial, but also human in terms of lost productivity, lives lost to suicide and broken families. Investment in mental illness research and services are – in NAMI's view – the highest priority for our nation and this Subcommittee.

National Institute of Mental Health (NIMH) Research Funding

The National Institute of Mental Health (NIMH) is the principal federal agency charged with funding biomedical research on serious mental illnesses. To inspire and support research that will continue to make a difference for people living with mental illnesses, and ultimately, promote recovery, NIMH developed a Strategic Plan in 2009 to guide future research efforts. The overarching objectives of the Strategic Plan are to: (1) promote discovery in the brain and behavioral sciences to fuel research on the causes of mental disorders; (2) chart mental illness trajectories to determine when, where and how to intervene; (3) develop new and better interventions that incorporate the diverse needs and circumstances of people with mental illnesses; and (4) strengthen the public health impact of NIMH-supported research.

Translating Research Advances into New Treatments

It is critical for us to move beyond the current universe of palliative treatments for serious mental illness. Even with optimal care, some children and adults living with serious mental illness will not be able to achieve recovery (as defined as permanent remission). As NIMH Director Dr. Tom Insel has noted, consumers and families need rapid, effective treatments that target the core pathophysiology of serious mental illnesses and the tools for early detection. Mental illness research can develop new diagnostic markers and treatments, but this will require defining the pathophysiology of these illnesses. NIMH now has the research tools necessary. Now is the time to set an ambitious goal of finding cures to these extremely disabling illnesses. However, NIMH must have the resources it needs to support this critical research agenda.

ARRA Investments

NAMI would like to draw the Subcommittee's attention to two specific critical investments NIMH is making as part of the American Recovery and Reinvestment Act (ARRA) and collaborations with the Department of Defense. The first is the RAISE (Recovery After an Initial Schizophrenia Episode) study which is being financed (in part) with \$368 million in ARRA funds. RAISE is the first ever large-scale trial exploring early and aggressive treatment integrating a variety of different therapies to reduce the symptoms and prevent the gradual deterioration of functioning that is characteristic in schizophrenia. The second is STARRS (Study to Assess Risk and Resilience in Service Members – a joint Army-NIMH study of suicide and mental health among military personnel. Army STARRS will identify – as rapidly as possible – modifiable risk and protective factors related to mental health and suicide. It also will support the Army's ongoing efforts to prevent suicide and improve soldiers' overall wellbeing.

Continuing the Federal Investment in Mental Illness Research

The President is proposing \$1.541 billion for basic scientific and clinical research at the National Institute of Mental Health (NIMH). This is a \$51 million increase above the current FY 2010 level of \$1.489 billion. While this is below the expected increase in biomedical research inflation, it is a tremendous accomplishment and endorsement of the importance of investment in medical research in a budget that proposes an overall freeze in domestic discretionary spending.

For FY 2011, NAMI supports the recommendations of the Ad Hoc Group on Medical Research for an overall NIH funding level of \$36 billion (a 12% increase over FY 2010). For NIMH, NAMI recommends a similar 12% increase, up to \$1.683 billion -- \$143 million above the President's request and \$193.6 million above the FY 2010 appropriation.

Funding for Programs at SAMHSA's Center for Mental Health Services (CMHS)

Mr. Chairman, as our nation continues to struggle through this current economic downturn and states struggle with diminished revenues, we are experiencing unprecedented strain in mental health service budgets. Since 2009, we have seen a combined total of nearly \$1.8 billion cut from state mental health authority (SMHA) budgets. In a number of states the spending reduction for mental health exceeds 20% of the entire SMHA budget. A few examples of the scale of these cuts to state mental health budgets include:

- Ohio - Combined state mental health authority cuts from 2009 through 2011 of 36.2% across the board or a \$191.3 million reduction,
- Rhode Island – A total percentage cut of 34% from 2007 to 2009 (from a statewide budget of \$82.1 million to \$54.5 million) – as a result the state is experiencing a 65% increase in the number of children with Serious Emotional Disturbance boarding in public emergency rooms,
- Illinois – Since 2009, 10,000 low income children and adults have lost access to community-based mental health care.
- Kansas -- New admissions to the state's public psychiatric hospitals have been frozen for the remainder of 2010 and nine of the state's 27 Community Mental

Health Centers are in operating deficits and in jeopardy of being closed (most of these agencies serve rural health professional shortage areas).

- Mississippi – The Governor has proposed an \$18 million cut this year that would result in the closing of six crisis centers and four Department of Mental Health facilities including two inpatient psychiatric hospitals.

When investments in treatment, support and recovery are slashed to this extreme degree, the costs to society and to government do not go away. Instead, the costs just get passed along far more expensively in terms of public spending and far less successfully in terms public health:

- Half of all lifetime mental illnesses begin by age 14 and without access to early diagnosis and treatment, we end up paying much more for special education, private placements, substance abuse and juvenile detention.
- Without access to community-based treatment and support, we end up paying much more for secondary medical symptoms, homelessness, addiction, broken families, extended hospital emergency admissions, nursing home beds, jails and prisons.
- Without access to mental health care, our national and state economies lose billions of dollars every year in unemployment, under-employment and lost productivity.
- Without access to treatment and recovery, people with serious mental illnesses are destined to die 25 years sooner than the general population.

At NAMI we refer to this as “spending money in all the wrong places” as the burden of untreated mental illness is shifted and hidden but no less at taxpayers expense.

It is imperative that programs at the Center for Mental Health Services (CMHS) at SAMHSA help states respond to the individual crises they are facing in trying to manage such deep reductions to community mental health budgets in a time of rising demand – both respect to the needs of the existing population of people living with serious mental illness and new populations at risk of anxiety, depression and psychosis.

In particular, this Subcommittee must expand investment in the Mental Health Block Grant (MHBG) for FY 2011. Funding for the MHBG has been frozen at its current level of \$420 million since FY 2000. **NAMI urges the Subcommittee to respond to this crisis at the state level by increasing funding for the Mental Health Block Grant by \$100 million to \$520 million in FY 2011.**

NAMI would also recommend the following priorities for CMHS for FY 2011:

- Support the President’s proposal to increase the PATH Homeless Formula Grant program to \$70 million (a proposed \$5 million increase above FY 2010),
- Support the President’s proposal for a \$5 million increase for the Children’s Mental Health program, boosting funding up to \$126 million, and

- Support the President's proposal for a \$6 million increase for suicide prevention activities at CMHS (up to \$54.2 million), including funding for the Garrett Lee Smith Memorial Act.

Addressing Chronic Homelessness and Mental Illness

SAMHSA's homeless programs fill a gap created by a preference *for funding housing capital needs over the critically important services* that are necessary for programs to be effective. In the recent competition conducted by SAMHSA the agency received over 500 qualified applications, of which the agency was only able to fund 68. The interest and capacity of providers to put these federal dollars to work and end homelessness for thousands of homeless individuals should demonstrate to Congress a clear mandate to significantly increase funding for SAMHSA's homeless programs.

The current FY 2010 funding level of SAMHSA homeless programs is \$75 million. This is divided between two accounts: \$32.25 million within the Center for Mental Health Services (CMHS) and \$42.75 within the Center for Substance Abuse Treatment (CSAT). The President's budget proposes an increase of \$12.1 million, \$7.446 million for CMHS and \$4.610 million for CSAT.

The President's 2011 budget proposal includes a new Homeless Initiative Program. This is a HUD/HHS partnership creating two demonstration programs, including one that couples Housing Choice Vouchers with services funding by Medicaid and SAMHSA. The Medicaid funds are mandatory spending and do not require an appropriations amount. However, the SAMHSA contribution must be appropriated and the President proposes \$15.8 million. This funding includes the \$12.1 million proposed SAMHSA homeless services increase and an additional \$3.7 million from existing CSAT resources.

NAMI applauds the Administration's recognition that the federal government can do a better job helping communities couple housing and services funding. This is a good first step. However, we are concerned that the chronically homeless demonstration would take \$3.7 million from existing resources and only states with existing 1115 Medicaid waivers can apply. NAMI urges this Subcommittee to ensure that an optimal number of states and public housing authorities, who administer Housing Choice Vouchers, can use the Medicaid and SAMHSA funding available for this program to more effectively target chronically homeless individuals living with mental illness.

Overall, NAMI urges this Subcommittee to provide \$120 million in SAMHSA homeless programs for essential mental health and substance use treatment services linked to permanent supportive housing for chronically homeless individuals and families. This request would increase funding by \$45 million over the FY 2010 funding level. NAMI also supports the President's recommendation for \$15.8 million for SAMHSA's portion of the Administration's Homeless Initiative Program for FY 2011.

Continue Progress on Addressing the Social Security Disability Claims and Appeals Backlog

Mr. Chairman, people with mental illness and other severe disabilities have been bearing the brunt of the backlog crisis for disability claims and appeals at Social Security. Behind the numbers are individuals with disabilities whose lives have unraveled while waiting for decisions – families are torn apart; homes are lost; medical conditions deteriorate; once stable financial security crumbles; and many individuals die. NAMI congratulates this Subcommittee on the progress made since 2008 with the appropriation for SSA’s Limitation on Administrative Expenses (LAE), boosting it to \$11.447 billion for FY 2010. This investment, along with ARRA funds to improve information technology has allowed SSA to hire new staff, reduce processing times and make progress on the reducing the disability claims backlog. **NAMI urges the Subcommittee to continue this progress and support the President’s recommendation for an LAE of \$12.521 billion for FY 2011.**

Conclusion

Chairman Obey, thank you for the opportunity to share NAMI’s views on the Labor-HHS-Education Subcommittee’s FY 2011 bill. NAMI’s consumer and family membership thanks you for your leadership on these important national priorities.

Michael Fitzpatrick

Michael Fitzpatrick is Executive Director of NAMI, the National Alliance on Mental Illness. Prior to January of 2004, he served both as the Director of NAMI's Policy Research Institute and as NAMI's National Director of Policy.

Mr. Fitzpatrick has served on numerous community, government and non-profit boards and expert panels. He has served as the President of the Board of the Long Term Care Ombudsman Program in his home state of Maine, and he presently serves as the Chair of the Campaign for Mental Health Reform. He also serves on the Board of REACH (Resource for Advancing Children's Health) Institute (2006).

Prior to joining NAMI in 1999, Mr. Fitzpatrick held senior management positions in state government, non-profit agencies, and the private sector where he developed successful education, employment, housing, outreach and rehabilitation programs.

Mr. Fitzpatrick has an MSW in Administration and Planning from Boston College. He also served in the Maine State Legislature, and from 1994-1996, he served as the House Chair of the Health and Human Services Committee.

Mr. OBEY. [Remarks made off microphone.]
Next, Julio Abreu, Coalition for Health Funding.

WEDNESDAY, MAY 12, 2010.

NATIONAL INSTITUTES OF HEALTH, CENTERS FOR DISEASE CONTROL, HEALTH RESOURCES AND SERVICES ADMINISTRATION, SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION, AGENCY FOR HEALTHCARE RESEARCH AND QUALITY, FEDERAL DRUG ADMINISTRATION, AND INDIAN HEALTH

WITNESS

JULIO ABREU, SENIOR DIRECTOR, GOVERNMENT AFFAIRS, MENTAL HEALTH AMERICA, ALEXANDRIA, VIRGINIA, COALITION FOR HEALTH FUNDING

Mr. ABREU. I have been called worse, Chairman.

Mr. OBEY. [Comments made off microphone.] [Laughter.]

Mr. ABREU. Good morning, Mr. Chairman and members of the Subcommittee. My name is Julio. I am President of the Coalition for Health Funding and Senior Director of Government Affairs at Mental Health America. I am pleased to offer this testimony on behalf of the Coalition regarding funding for agencies and programs of the U.S. Public Health Service, including NIH, CDC, HRSA, SAMHSA, and AHRQ.

Since 1970, the Coalition has advocated for sufficient and sustained discretionary funding for the public health continuum to meet the mounting and evolving health challenges confronting the American people. We acknowledge and applaud the longstanding support of public health programs from the Subcommittee, particularly that of the Chairman. And I want to echo our deep gratitude for your tremendous leadership.

Our diverse membership, representing the interest of over 50 million patients, providers, researchers, and public health professionals, supports the belief that the public health agencies and programs are essential for improving health and health care through greater access, higher quality, lower costs, improved safety, faster cures, and ultimately healthier people.

The Coalition's pressing and immediate goals are to: one, build the capacity for our public health system; two, address America's mounting health needs under the weight of an ongoing recession and aging population, a health workforce shortage, and rising rates of chronic disease; and, three to support the implementation of the Patient Protection and Affordable Care Act, a new health care reform legislation, PPACA.

Given the current fiscal challenges, the Coalition appreciates the funding increases proposed in the President's fiscal year 2011 budget for public health programs. We are also grateful to you and your colleagues for the mandatory funding stream for public health, now provided through health reform, to augment discretionary funding for the existing public health infrastructure.

We hope Congress will seize the opportunity to increase momentum for health system transformation by further investing in the public health continuum, building on previous discretionary invest-

ments in the public health service, and making permanent capacity created by ARRA.

We also hope Congress will resist the urge to look to the Mandatory Public Health and Prevention Fund provided in PPACA as a means to supplant current discretionary public health funding, as this mandatory investment was intended to make whole the existing public health infrastructure and support innovative cross-cutting programs to transform the ways in which public health services are delivered.

These transformational investments will help lead the Nation toward a more community-oriented accountable approach to public health, which will in turn decrease our Nation's health care costs and make America healthier.

The public health infrastructure has experienced significant erosion over the past several years, despite its important role in keeping Americans healthy, productive, and secure. Federal spending for public health has been flat for nearly five years, and our States around the Country have cut more than \$392 million for public health programs in just the past year. These shortfalls have left communities struggling.

Federal discretionary investment in public health service represents only a fraction of our Nation's total health care spending, just 2 percent in 2008 based on expenditure data from CMS, even though the public health continuum has the potential to slow sustainable growth in mandatory costs. Our Nation's lost opportunity to save lives and money through investments in the public health continuum is possibly best represented by the Medicare program. A study published in Health Affairs finds that the causes of Medicare spending growth have changed dramatically in two decades, where Medicare's skyrocketing costs are now mostly attributable to the treatment of preventable chronic conditions such as diabetes, conditions that could have been prevented with a more serious investment in public health.

We listened to you, Mr. Chairman. We have been working with our other public health organizations and have 300 of them signed up with five former surgeon generals urging Congress to invest in public health.

Let me close by saying that while I am not a musician, I bet I can get the public health community to join and perhaps create a band to go around the Country to make a compelling case for the need to invest in public health. Thank you for this opportunity, Mr. Chairman.

[Written statement by Julio Abreu follows:]

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Julio Abreu

Senior Director, Government Affairs
Mental Health America
Alexandria, Virginia

~ for ~

Coalition for Health Funding

Washington, DC

House Labor, Health and Human Services, Education and Related
Agencies Appropriations Subcommittee

Wednesday, May 12, 2010
10:00 a.m.

Summary: This testimony offered on behalf of the Coalition for Health Funding recommends an \$8.7 billion increase over FY 2010 for agencies and programs of the U.S. Public Health Service under the subcommittee's jurisdiction, including the National Institutes of Health, Centers for Disease Control and Prevention, Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration, and the Agency for Healthcare Research and Quality. Since 1970, the Coalition for Health Funding has advocated for sufficient and sustained discretionary funding for the public health continuum to meet the mounting and evolving health challenges confronting the American people.

On behalf of the Coalition for Health Funding, I am pleased provide the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on FY 2011 funding levels for the agencies and programs of the U.S. Public Health Service (PHS). Since 1970, the Coalition for Health Funding has advocated for sufficient and sustained discretionary funding for the public health continuum to meet the mounting and evolving health challenges confronting the American people.

Our diverse membership—representing the interests of over 50 million patients, providers, researchers, and public health professionals—supports the belief that the PHS agencies and programs are essential for improving health and health care through greater access, higher quality, lower costs, improved safety, faster cures, and ultimately, healthier people. Investment in the public health continuum will show dividends through biomedical, behavioral and health services research, community based prevention strategies, basic and targeted health services for the medically underserved, and safety and surveillance. The Coalition also supports education and training of a range of health and public health professionals to ensure we have an adequate workforce to meet the health needs of Americans. These include not only primary care physicians, but nurses, dentists, mental health professionals, public health professionals, physician assistants, and other allied health professionals.

The Coalition's pressing and immediate goal is to build the capacity of our public health system to support the implementation of the Patient Protection and Affordable Care Act and address America's mounting health needs under the weight of an ongoing recession, an aging population, a health workforce shortage, and persisting declines in health status. Given current fiscal challenges, the Coalition for Health Funding appreciates the funding increases proposed in the President's FY 2011 budget for public health programs that prevent and cure disease, promote well-being, support the disabled, regulate food and drugs, and provide safety net access to a range of health and behavioral health services for millions of Americans who lack health insurance. In addition, we are grateful to Congress for the mandatory funding stream for public health now provided through health reform to augment discretionary funding for the existing public health infrastructure and to bolster select prevention and wellness programs.

We hope Congress will seize the opportunity to increase momentum for health system transformation by further investing in the public health continuum, building on previous discretionary investments in the PHS and making capacity created by the American Recovery and Reinvestment Act (ARRA) permanent. We also hope Congress will resist the urge to look to the mandatory funding for public health provided in the Patient Protection and Affordable Care Act as a means to supplant current discretionary public health funding, as this mandatory investment was intended to augment the existing infrastructure and strengthen targeted programs.

The public health infrastructure has experienced significant erosion over the past several years, despite its important role in keeping Americans healthy, productive, and secure. The fragility of the public health infrastructure is discussed in a recent report by Trust for America's Health and the Robert Wood Johnson Foundation. Federal spending for public health has been flat for nearly five years, and states around the country have cut more than \$392 million for public health

programs in just the past year. These shortfalls have left communities around the country struggling to deliver basic disease prevention and emergency health preparedness services.ⁱ

Federal discretionary investment in the PHS represents a fraction of our nation's health care spending—just two percent in 2008 based on expenditure data from the Centers for Medicare and Medicaid Services—even though the public health continuum has the potential to slow unsustainable growth in mandatory costs, reduce lost productivity at work, school, and home, and strengthen every citizen's contribution for a healthy, economically strong America. Medicare represents possibly the best example of a lost opportunity to save lives and money through investment in the public health continuum. A study published recently in *Health Affairs* finds that the causes of Medicare spending growth have changed dramatically in two decades, where Medicare's skyrocketing costs are now mostly attributable to the treatment of preventable chronic conditions such as diabetes, arthritis, hypertension, and kidney disease—conditions that could have been prevented with a more serious investment in public health.ⁱⁱ

Congress has made historic strides toward comprehensive health system change—which begins, not ends, with the enactment of the Patient Protection and Affordable Care Act. As the administration undertakes the Herculean task of implementing this new law, the PHS and its myriad programs will be essential to achieving the law's goals of improved health and health care. Without significant and sustained discretionary funding in FY 2011 and beyond, the PHS will lack the capacity to deliver on the law's promises of improved health care quality, availability, and affordability. Only with a significant investment in the public health infrastructure can we build capacity to transform our health system from one that reacts when people are sick to one that proactively keeps people healthy. That's the best way to truly bend the cost curve.

The Coalition for Health Funding urges the Subcommittee to invest in the public health continuum and join 300 health organizations and five former Surgeon Generals that, in a letter dated March 17, urged Congress to invest in the PHS. As that letter states:

“The FY 2011 budget provides an opportunity to increase momentum for health reform...With sustained and stable investment, the public health continuum will keep America healthy and ‘bend the cost curve’ by preventing costly chronic diseases, stemming the cause of disability, including behavioral and developmental disorders, identifying the most effective treatments, discovering new therapies and cures, developing a robust health workforce, and protecting our food and drug supply.”

The following list summarizes the Coalition for Health Funding's FY 2011 funding recommendations for agencies of the PHS under the Subcommittee's jurisdiction. The Coalition developed these recommendations through a consensus process with other health coalitions that advocate for specific agencies.

National Institutes of Health (NIH)

The Coalition supports \$35 billion in FY 2011 for the National Institutes of Health, a 12 percent increase over FY 2010 funding level and a 9 percent increase over the President's FY 2011 request. This request would make permanent NIH's current research capacity, which includes

ARRA dollars, allowing the nation to seize the opportunity to build on the tremendous momentum emerging from this strategic investment. NIH invested ARRA funds in a range of potentially revolutionary new avenues of research that will lead to new early screenings and treatments for disease. Moreover, this investment is directly sparking economic revitalization in hundreds of communities through funding local universities, small businesses, and research institutions, and it remains vital to the nation's long-term competitiveness in a key economic sector.

At a time when more than half of the top growing occupations are health care or research related, we should make the new NIH research capacity permanent, ensuring that the nation does not shelve emerging discoveries, dismantle labs, and discourage new scientists at this crucial time, and instead builds on current progress to further help the American public.

Centers for Disease Control and Prevention (CDC)

The Coalition for Health Funding recommends a level of \$8.8 billion for CDC's core programs in FY 2011, a 36 percent increase over FY 2010 and a 39 percent increase over the President's FY 2011 request. This amount reflects the professional judgment budget of former CDC Director Julie Gerberding and is representative of what CDC needs to fulfill its core mission in FY 2011; activities and programs that are essential to protect the health of the American people. CDC is faced with unprecedented challenges and responsibilities, ranging from bioterrorism preparedness to helping the nation prepare for the impacts of climate change. CDC funds myriad programs in: injury control and violence prevention; health promotion, nutrition and chronic disease prevention; oral health; maternal and child health; antimicrobial resistance and infectious diseases; and health data collection. It is notable that more than 70 percent of CDC's budget supports states and local health organizations, which rely on CDC funding now more than ever as they grapple with increased demands for services and declining state and local resources due to the ongoing recession.

The Coalition is disappointed the President proposes to cut more than \$130 million from CDC's budget in FY 2011 despite the critical importance of CDC's programs in promoting prevention and wellness, a key priority of this Administration. This erosion of investment is particularly troubling when chronic diseases continue to rise and drive health care costs upward and the public health infrastructure that will support the goals of health reform is crumbling and facing significant job losses after years of neglect. We must make up the lost ground and fully fund CDC's core public health programs at a time when the threats to public health are so great.

Health Resources and Services Administration (HRSA)

The Coalition for Health Funding recommends an overall funding level of \$9.15 billion for HRSA in FY 2011, a 22 percent increase over FY 2010 and the President's FY 2011 request. Through its programs in every state and thousands of communities across the country, HRSA is a national leader in providing health services for individuals and families, serving as a health safety net for the medically underserved. Relatively level funding over the past several years has hindered the growth of HRSA's successful programs, and a more significant investment is needed for the agency to achieve its mission: ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and health care infrastructure.

As the administration implements health reform, the Coalition believes \$9.15 billion is needed for HRSA to build the foundation for improved health service delivery, to expand the health care workforce, to smoothly transition vulnerable populations to a new health system, and to continue to the nation's safety net programs.

Substance Abuse and Mental Health Services Administration

The Coalition for Health Funding recommends an overall funding level of \$3.932 billion for SAMHSA in FY 2011, a 15 percent increase over FY 2010 and an 11 percent increase over the President's FY 2011 request. An October 6 national survey shows that the economic downturn is taking a toll on the mental health of Americans. Individuals who are unemployed are four times as likely as those with jobs to report symptoms consistent with severe mental illness. Americans who experienced involuntary changes in their employment status, such as pay cuts or reduced hours, also are twice as likely to have these symptoms, even though they are employed full time. And SAMHSA reports that calls into the Suicide Hotline averaged nearly 50,000 calls a month in 2009—a substantial increase from previous years.

As you know, this population is already vulnerable. For example, a 2006 report indicated that persons with serious mental illness die, on average, 25 years earlier than the general population, and we know that the suicide rate of approximately 33,000 persons a year is nearly twice the number of homicides per year.

Agency for Healthcare Research and Quality

The Coalition for Health Funding recommends an overall funding level of \$611 million for AHRQ in FY 2011, consistent with the President's FY 2011 request. AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. The President's FY 2011 request will allow AHRQ to generate more and better evidence to help make a measurable difference in health care for all Americans, strengthening its critical health care safety, quality, and efficiency initiatives.

The Coalition for Health Funding appreciates this opportunity to provide its FY 2011 funding recommendations for the PHS and looks forward to working with the Subcommittee in the coming weeks and months.

¹ Trust for America's Health, *Shortchanging America's Health: A State-by-State Look at How Public Health Dollars Are Spent*, March 2010. Available online at: <http://healthyamericans.org/report/74/federal-spending-2010>.

² Thorpe, K.E., et al. "Chronic Conditions Account for Rise in Medicare Spending from 1987-2006." *Health Affairs*, Vol. 29, No. 4, Feb. 18, 2010, pp. 718-724. Available online at <http://content.healthaffairs.org/cgi/content/abstract/hlthaff.2009.0474>.

Julio Cesar Abreu**PROFESSIONAL EXPERIENCE**

| <u>Years</u> | <u>Agency, Title, Major Responsibilities</u> |
|----------------|--|
| Apr 01-Present | <p><i>Senior Director, Government Affairs, Mental Health America, Washington, DC.</i></p> <ul style="list-style-type: none"> • Direct Appropriations and Budget strategies for funding of the mental health portfolio including treatment, prevention and children's anti-violence initiatives. • Represent MHA before the Administration and Capitol Hill, including the Congressional Black Caucus and the Congressional Hispanic Caucus. • Leadership positions in a variety of coalitions including: President of the Coalition for Health Funding; Co-Chair and Board Member of the Mental Health Liaison Group; and a Board Member of the Consortium for Citizens with Disabilities (CCD). • Lead efforts in the development of Juvenile Justice plans and strategies including coordination with our Board members and coalition partners. • Develop and nurture working relationships with the Department of Health and Human Services, including senior staff at the Substance Abuse and Mental Health Services Administration and the National Institutes of Health. • Coordinate strategies for our Education portfolio including the reauthorization of the Elementary and Secondary Education Act (NCLB) and the Individuals with Disabilities Education Act (IDEA). |
| Feb 97-Mar 01 | <p><i>Deputy Director, Government Affairs, AIDS Action, Washington, DC.</i></p> <ul style="list-style-type: none"> • Lead efforts in the development of HIV prevention plans and strategies, including coordination with our Board members and coalition partners. • Represent AIDS Action before the Administration and Capitol Hill, including the Congressional Black Caucus and the Congressional Hispanic Caucus. • Develop, maintain and advance working relationships with the Department of Health and Human Services, including senior staff at the Centers for Disease Control and Prevention, and the Health Resources and Services Administration. • Coordinate Appropriations and Budget strategies for the funding of the HIV/AIDS portfolio including prevention, care, research, and the global AIDS initiative. • Organize efforts to provide a voice for patients/consumers, as well as building consensus on the federal managed care legislation by working with Congress and coalition partners. • Co-direct the prevention working group for the National Organizations Responding to AIDS (NORA), a coalition of 175 public health, labor, civil rights, religious and international organizations. • Manage our prevention grant with the CDC – coordinating various forums and documents for our network. |

May 93-Feb 97 **Senior Policy Advocate, Human Rights Campaign (HRC)**, Washington, DC.

- Coordinated public health and civil rights priorities, and message development for Capitol Hill.
- Organized efforts with the business and labor community to drum up support for anti-gay employment discrimination bill.
- Briefed congressional members on a variety of issues specific to the lesbian and gay communities.
- Scheduled, organized, and moderated HRC town hall meetings throughout the organization's southern, mid-western, and western regions.
- Determined viability and endorsement of candidates, then worked on campaigns for U.S. House of Representative candidate Walter Capps, Santa Barbara, CA; and U.S. Senate candidate Sam Coppersmith, Arizona.
- Educated and organized local communities on political issues impacting their areas, occasionally working with development departments.
- Assisted in state coordination and mobilization of voters.
- Increased visibility for HRC at presidential political convention.

Dec 90-May 93 **Legislative Specialist, Clerk of the House of Representatives, US House of Representatives**, Washington, DC.

- Researched, prepared and drafted legislative portfolios for congressional offices.
- Monitored daily legislative activities.
- Organized and prepared federal legislation analysis according to congressional office priorities.
- Instructed congressional staffs on the legislative process.

EDUCATION

| <u>Year</u> | <u>Degree</u> | <u>Institution, Major Area</u> |
|-------------|---------------|--|
| 1990 | B.A. | University of Illinois, Urbana-Champaign, IL. Major: Political Science |

References Available Upon Request

Mr. OBEY. [Remarks made off microphone.]
Next, James Sykes, AIDS Institute.

WEDNESDAY, MAY 12, 2010.

**CENTERS FOR DISEASE CONTROL, HEALTH RESOURCES
AND SERVICES ADMINISTRATION, AND NATIONAL IN-
STITUTES OF HEALTH**

WITNESS

JAMES SYKES, DIRECTOR OF GLOBAL PROGRAMS, POLICY AND ADVOCACY, AIDS INSTITUTE

Mr. SYKES. Good morning, Mr. Chairman and Subcommittee members. The AIDS Institute is pleased to be here today to comment in support of funding domestic HIV/AIDS and hepatitis programs. We thank you for your support of these programs over the years and trust that you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

HIV/AIDS remains one of the world's worst health pandemics in history. To date, nearly 600,000 people have died of AIDS in the U.S. Over 1.1 million people in the U.S. are living with HIV/AIDS, and there is a new infection every nine and a half minutes. Persons of minority races and ethnicities are disproportionately affected, as well as the poor. About 70 percent of those infected rely on publicly funded health care.

Despite the growing need, domestic HIV/AIDS programs have experienced only very minor increases in recent years. We hope you will support President Obama's desire to increase funding for these important public health programs. Federal funding is particularly critical at this time, since State and local government budgets are being severely cut during this economic downturn, while demand for services are escalating due to the fact that people are living longer, people are losing their health insurance, and HIV testing programs are identifying more people who have HIV.

Of immediate importance is our request of \$126 million in emergency funding this year for the AIDS Drug Assistance Program. ADAPs provide lifesaving HIV drug treatment to over 150,000 people, the majority of whom are people of color and very poor. Currently, ADAPs are experiencing unprecedented growth. The monthly growth rate of nearly 1300 clients is an increase of 80 percent from fiscal year 2008.

Due to the economic crisis, State contributions to the programs have dropped from \$329 million to \$214 million in just one year. Meanwhile, the Federal share of the ADAP program has dropped to only 49 percent, compared to 69 percent in 2000.

Due to the lack of funding, States have instituted waiting lists and have reduced the number of drugs on their formularies, reduced eligibility, and capped enrollment. There are currently 1,056 persons in 10 States on ADAP waiting lists as of today. In order to address the ADAP funding crisis, which will grow much worse in fiscal year 2011, we are requesting an increase of \$370 million. To address the immediate situation, the AIDS Institute requests

\$126 million of those funds in fiscal year 2010 as part of an emergency supplemental.

We are very pleased that just last week 66 members of the House sent a letter to President Obama in support of this emergency funding for ADAP.

For fiscal year 2011, the President requested an increase of only \$39.5 million, or just 1.7 percent for the entire Ryan White Program, which includes ADAP; and no increase for Parts A and D of the program.

The AIDS Institute urges the Subcommittee to consider the growing needs of all parts of the Program and provide the necessary resources it requires to meet the needs of people living with HIV/AIDS in the U.S.

Nearly two years ago, the CDC increased its estimate of new infections per year by 40 percent. In order to reverse that trend, the CDC is going to need additional resources so that it can scale up HIV prevention. But currently we only allocate about 3 percent of our total HIV/AIDS spending on domestic prevention.

Unfortunately, the requested \$31 million increase by the President is far from what is needed to reduce the number of new HIV infections. We would, however, like to commend the President for focusing much of this increase on gay men, who represent a majority of HIV cases in the U.S. and is the only group in which HIV incidence is increasing.

Investing in prevention today will save money tomorrow. Every case of HIV that is prevented saves, on average, \$355,000 of lifetime treatment costs. That translates into nearly \$20 billion in annual future medical costs for the 56,300 new infections that occur every year.

As detailed in our written statement, the AIDS Institute supports additional funding for AIDS research at NIH, the Minority AIDS Initiative, the CDC's Viral Hepatitis Division. We also appreciate the Committee's support for funding of syringe exchange and comprehensive sex education programs, two proven HIV prevention programs.

Again, the AIDS Institute appreciates the opportunity to appear before you today, and thank you for your continued support. Thank you, sir.

[Written statement by James Sykes follows:]



THE AIDS INSTITUTE

May 12, 2010

**WRITTEN STATEMENT OF
JAMES SYKES, DIRECTOR OF GLOBAL PROGRAMS, POLICY AND ADVOCACY
THE AIDS INSTITUTE
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND
RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS**

Dear Chairman Obey and Members of the Subcommittee:

The AIDS Institute, a national public policy research, advocacy, and education organization, is pleased to comment in support of critical HIV/AIDS and Hepatitis programs as part of the FY2011 Labor, Health and Human Services, Education and Related Agencies appropriation measure. We thank you for your support of these programs over the years, and trust you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

HIV/AIDS

HIV/AIDS remains one of the world's worst health pandemics in history. According to the CDC, 583,298 people have died of AIDS in the U.S. In 2008, the CDC announced that its estimate of new infections per year is now 56,300, or 40 percent higher than previous estimates. This translates into a new infection every 9 ½ minutes. At the end of 2007, an estimated 1.1 million people in the U.S. were living with HIV/AIDS.

Persons of minority races and ethnicities are disproportionately affected by HIV/AIDS. African Americans, who make up 13% of the US population, account for half of HIV/AIDS cases. HIV/AIDS also disproportionately affects the poor, and about 70 percent of those infected rely on publicly funded health care.

The U.S. government has played a leading role in fighting HIV/AIDS, both here and abroad. The vast majority of the discretionary programs supporting HIV/AIDS efforts domestically are funded through your Subcommittee.

We are keenly aware of budget constraints and competing interests for limited dollars. Unfortunately, despite the growing need, domestic HIV/AIDS programs have experienced only very minor increases in recent years. We are pleased that President Obama continues to focus on domestic HIV/AIDS programs and has proposed increases for prevention and treatment. We hope you will support the President's desire and increase funding for these important public health programs. *Federal funding is particularly critical at this time since state and local budgets are being severely cut during this economic downturn.* Many states and local governments have cut their HIV

prevention and HIV/AIDS care programs at the very same time demand for services are escalating.

Below are The AIDS Institute's program requests and supporting explanation:

Centers for Disease Control and Prevention-HIV Prevention and Surveillance

| | |
|---------------------------|-----------------|
| FY2010: | \$728 million |
| FY2011 Community Request: | \$1,606 million |

As stated above, the CDC has increased the estimate of people infected each year by 40 percent. New infections are occurring particularly in certain populations, including African-American men and women and men who have sex with men. In order to address the specific needs of these populations and the increased number of people infected, CDC will need additional funding. Currently, the United States spends only about 3 percent of its HIV/AIDS spending on domestic prevention.

The AIDS Institute is extremely supportive of President Obama's budget request to "begin a focused initiative to prevent HIV through holistic and integrated approaches to protect the health of gay, bisexual, and other MSM." We congratulate the President for proposing additional funding and for focusing it on gay men, which represent a majority of HIV cases in the U.S and is the only group in which HIV incidence is increasing.

Unfortunately, the requested \$31 million increase is far from what is needed to significantly reduce the number of new HIV infections. According to the CDC's professional judgment budget, an additional \$878 million for each of the next five years is necessary to improve HIV prevention efforts and reduce HIV transmission in the United States. *Therefore, The AIDS Institute supports an increase for CDC HIV prevention funding by \$878 million in FY11.*

This funding would be targeted to: 1) Increasing HIV testing and the number of people who are reached by effective prevention programs; 2) developing new tools to fight HIV with scientifically-proven interventions; and 3) improving systems to monitor HIV and related risk behaviors, and to evaluate prevention programs.

Investing in prevention today will save money tomorrow. Every case of HIV that is prevented saves, on average, \$355,000 of lifetime treatment costs. That translates into nearly \$20 billion in annual future medical costs for the 56,300 new HIV infections that occur every year.

In order to implement the goals and objectives that will be contained in the National HIV/AIDS Strategy, which will be released by the President this summer, additional resources will be necessary. At a time when state and local HIV prevention budgets are being cut, maintaining current funding levels will require a level of resources greater than what has been proposed.

The AIDS Institute is concerned about any effort that would actually reduce the level of HIV prevention dollars at the state level. *That is why we are opposed to language requested by the Administration that would allow states to move up to 10 percent of its CDC funding, including HIV funding, to address the top six leading causes of death.*

Ryan White HIV/AIDS Programs

FY2010: \$2,290.9 million
 FY2011 Community Request: \$3,101.5 million

The centerpiece of the government's response to caring and treating low-income people with HIV/AIDS is the Ryan White HIV/AIDS Program. Ryan White currently serves over half a million low-income, uninsured, and underinsured people. In FY10, the Program received an increase of \$53 million, or just 2.3 percent. This increase does not even cover the rate of inflation. The AIDS Institute urges you to provide substantial funding increases to all parts of the Ryan White Program. Consider the following:

1) Caseload levels are increasing. People are living longer due to lifesaving medications; there are over 56,000 new infections each year; and according to the CDC, increased testing programs will identify 12,000 to 20,000 new people infected with HIV each year. With rising unemployment, people are losing their employer-sponsored health coverage.

2) State and local budgets are experiencing cutbacks due to the economic downturn. A recent survey by the National Alliance of State and Territorial AIDS Directors found that state HIV/AIDS funding reductions totaling more than \$170 million occurred in 29 states during FY09. The situation for this year and next will be even worse. Thirty-three states who participated in the survey anticipate a decrease in state funding this year.

3) There are significant numbers of people in the U.S. who are not receiving life-saving AIDS medications. An IOM report concluded that 233,069 people in the U.S. who know their HIV status do not have continuous access to Highly Active Antiretroviral Therapy.

Specifically, The AIDS Institute requests the following funding levels for each part of the Program:

Part A provides medical care and vital support services for persons living with HIV/AIDS in the metropolitan areas most affected by HIV/AIDS. We request an increase of \$225.9 million, for a total of \$905 million.

Part B base provides essential services including diagnostic viral load testing, viral resistance monitoring, and HIV care to all 50 states, DC, Puerto Rico, and the territories. We are requesting a \$55.9 million increase, for a total of \$474.7 million.

The **AIDS Drug Assistance Program (ADAP)** provides life-saving HIV drug treatment to over 150,000 people, the majority of whom are people of color (65%) and very poor (77% are at or below 200% of the federal poverty level). Currently, ADAPs are experiencing unprecedented growth. The monthly growth of 1,271 clients is an increase

of 80 percent from FY2008 when ADAPs experienced an average monthly growth of 706 clients. State contributions to the program have dropped from \$329 to \$214 million in just one year. Meanwhile, the federal share of the ADAP program has dropped to only 49 percent, compared to 69 percent in 2000. Due to a lack of funding, states have instituted waiting lists and have reduced the number of drugs on their formularies, reduced eligibility and capped enrollment. There are currently 1,001 people in 11 states on ADAP waiting lists. In order to address the ADAP funding crisis, which will grow even worse in FY11, we are requesting an increase of \$370.1 million for a total of \$1,205.1 million. To address the immediate situation, The AIDS Institute requests \$126 million of those funds in FY10 as part of an Emergency Supplemental.

Part C provides early medical intervention and other supportive services to over 248,000 people at over 380 directly funded clinics. We are requesting a \$131 million increase, for a total of \$337.9 million.

Part D provides care to over 84,000 women, children, youth, and families living with and affected by HIV/AIDS. This family-centered care promotes better health, prevents mother-to-child transmission, and brings hard-to-reach youth into care. We are requesting a \$7.0 million increase, for a total of \$84.8 million.

Part F includes the AIDS Education and Training Centers (AETCs) program and the Dental Reimbursement program. We are requesting a \$15.2 million increase for the AETC program, for a total of \$50 million, and a \$5.4 million increase for the Dental Reimbursement program, for a total of \$19 million.

For FY11, the President requested an increase of only \$39.5 million, or just 1.7 percent, for the entire Ryan White Program and no increase for Parts A and D of the Program. The AIDS Institute urges the Subcommittee to consider the growing needs of all parts of the Ryan White Program and provide the necessary resources it requires to meet the needs of people living with HIV/AIDS in the U.S.

National Institutes of Health-AIDS Research

| | |
|----------------------------|---------------|
| FY 2010: | \$3.1 billion |
| FY 2011 Community Request: | \$3.5 billion |

The NIH conducts research to better understand HIV and its complicated mutations, discover new drug treatments, develop a vaccine and other prevention programs such as microbicides, and ultimately develop a cure. The critically important work performed by the NIH not only benefits those in the U.S., but the entire world. This research has already helped in the development of many highly effective new drug treatments, prolonging the lives of millions of people. As neither a cure nor a vaccine exists, and patients continue to build resistance to existing medications, additional research must continue. NIH also conducts the necessary behavioral research to learn how HIV can be prevented best in various affected communities. We ask the Committee to fund critical AIDS research at the community requested level of \$3.5 billion.

Comprehensive Sex Education

President Obama and Congress took steps toward implementing comprehensive sexual education in FY10 by ending discretionary funded abstinence-only until marriage programs and creating the Teen Pregnancy Prevention Initiative. We urge the Congress to continue no funding for abstinence only education programs. Additionally, we believe the Teen Pregnancy Prevention Initiative should be expanded so that it addresses other aspects of sexual health, including HIV and STD prevention.

Syringe Exchange Programs

By eliminating the federal funding ban on syringe exchange programs in FY10, Congress allowed funding of a proven method to reduce the transmission of HIV and other infectious diseases. The AIDS Institute requests that you work to ensure that this ban is not reinstated.

Minority AIDS Initiative

The AIDS Institute supports increased funding for the Minority AIDS Initiative (MAI), which is funded by numerous federal agencies. MAI funds services nationwide that address the disproportionate impact that HIV has on communities of color. We are requesting a \$207.1 million increase across the MAI's programs, for a total of \$610 million.

Viral Hepatitis

The Institute of Medicine (IOM) recently released a report **Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C**. It outlines a number of recommendations on how the incidence of Hepatitis B & C infections can be decreased. These recommendations include increased public awareness campaigns, heightened testing and vaccination programs, continued research, along with improved surveillance and other prevention programs.

According to the IOM, 3.5–5.3 million people, or 1-2 percent of the US population are living with chronic Hepatitis B or C. There are an estimated 43,000 new acute Hepatitis B infections each year in the US. The CDC estimates that 10 percent of people with Hepatitis B are co-infected with HIV and 25 percent of people with Hepatitis C are co-infected with HIV.

Congress currently funds CDC's Viral Hepatitis Division at only \$19.3 million. Given the huge impact that Hepatitis B & C have on the health of so many people, and the large treatment costs, The AIDS Institute urges the federal government to make a greater financial commitment to Hepatitis prevention. The AIDS Institute requests an increase of \$30.7 million for the program, for a total of \$50 million.

The AIDS Institute asks that you give great weight to our testimony as you deliberate over the FY2011 appropriation bill. Should you have any questions or comments, feel free to contact Carl Schmid, Deputy Executive Director, The AIDS Institute (202) 462-3042 or cschmid@theaidsinstitute.org. Thank you very much.

James Sykes, MPH
Director of Global Programs, Policy, and Advocacy
The AIDS Institute

James Sykes is the Director of Global Programs, Policy, and Advocacy for The AIDS Institute, a national nonprofit, public policy, research, advocacy, and education organization located in Washington, DC and Tampa, FL. Prior to assuming his current position, he served as Global Program Coordinator, Assistant to the Executive Director, and Community Educator for the organization.

During his more than 14 years of experience in HIV/AIDS, he has acted as Health Education and Prevention Manager for the National AIDS Education & Services for Minorities, Inc., Atlanta, Georgia, during which he also served as Chair of the Prevention Interventions Committee of the Georgia Statewide Community Planning Group.

His previous experience includes working as Director of Community Health Services and Medical Educator for the Tampa AIDS Network, Tampa, Florida, where he developed and implemented a medical adherence program for African American clients.

Mr. Sykes earned a Master of Public Health degree with a concentration in community health education and a Bachelor of Arts degree in Biology from the University of Tennessee, Knoxville. He also pursued post-baccalaureate studies in Biochemistry at the University of Georgia, Athens, and basic sciences at the Morehouse School of Medicine, Atlanta, Georgia.

Mr. OBEY. [Remarks made off microphone.] [continuing]. Have written the Committee asking for increased funding. I am sure most of them are consistent, but there are more than a few members in Congress who will sign every blessed letter that comes along asking for more money, and then they will vote against the bill that contains the money when it comes to the Floor and kick the hell out of us for saying it contains too much money.

Mr. SYKES. I understand.

Mr. OBEY. So if you can help us to avoid giving hypocrisy a bad name, it would be appreciated. [Laughter.]

Mr. SYKES. Give me the names of those members, sir, and we would gladly call on them.

Mr. OBEY. Next, Dr. Heidi Chumley, Health Professions and Nursing Education Coalition.

WEDNESDAY, MAY 12, 2010.

TITLE VII AND VIII

WITNESS

DR. HEIDI CHUMLEY, SENIOR ASSOCIATE DEAN OF MEDICAL EDUCATION, UNIVERSITY OF KANSAS MEDICAL CENTER, HEALTH PROFESSIONS AND NURSING EDUCATION COALITION

Dr. CHUMLEY. Good morning. My name is Dr. Heidi Chumley, and I am a family physician and the Senior Associate Dean for Medical Education at the University of Kansas School of Medicine.

Like most academic family physicians, I have a firsthand appreciation for HRSA's health profession programs, as they have supported my work throughout the various stages of my career. So it is a pleasure to testify today on behalf of the Health Professions and Nursing Education Coalition, or HPNEC, an alliance of more than 60 national organizations representing schools, programs, health professionals, and students dedicated to ensuring the health care workforce is trained to meet the needs of the diverse population.

I am here to speak with you about the Title VII health professions and Title VIII nursing programs, which enhance the supply of the diversity and the distribution of health care workforce by supporting the education of health professionals.

In particular, these programs emphasize primary care and training in interdisciplinary settings. With the recent enactment of health reform legislation, the Nation will need a robust, diverse health care workforce to meet the increased demands for care.

HPNEC recommends \$600 million to sustain and strengthen the existing Title VII and Title VIII programs in fiscal year 2011. As you know, PPACA updated and restructured the existing health professions programs to improve their efficiency, effectiveness, and accountability. The legislation also authorized several new programs and initiatives designed to help mitigate health workforce challenges.

Many HPNEC members are enthusiastic about the opportunities afforded through these newly authorized workforce programs. As a coalition, HPNEC encourages an investment in these new pro-

grams that supplements, but does not replace, support for the existing Title VII and Title VIII programs.

We are grateful to the Chairman and this Subcommittee for the increases provided for many of the health professions programs in recent years, and for the Subcommittee's longstanding support.

These investments are crucial to addressing existing and looming provider shortages throughout the Country. According to HRSA, over 30,000 health practitioners are needed today to allay existing shortages. Further, within the next 10 to 20 years, the Nation faces shortages of 200,000 physicians, including at least 46,000 primary care professionals, a million nurses, 38,000 pharmacists, 250,000 public health professionals, and 40,000 geriatricians and geriatric social workers, as well as shortages among dental, allied health, mental health, and other providers.

These shortages, combined with faculty shortages, racial and ethnic disparities, and shortages of health professionals in rural and other underserved areas will take time to reverse. We must make appropriate investments in the education and training of health professionals today to truly extend health care access to all segments of the population.

At KMC, where I am from, Title VII and Title VIII grants work to alleviate these strains on the system. Primary care loans incentivize financially needy students to choose primary care; nursing loans help students pursue a diploma, associate, baccalaureate, or graduate degree in nursing; and scholarships help disadvantaged students pursue a health professions degree.

In the last five years along, KU has given out over 400 Title VII and Title VIII funded scholarships and loans to help students pursue a career in the health professions.

Faculty and staff have also benefitted from grants, helping boost faculty development in primary care, as well as supporting the Central Plains Geriatric Education Center Consortium. Additionally, thanks to ARRA, our Minority Centers of Excellence Program and our Health Careers Opportunity Program can still operate today, providing mentorship and guidance to aspiring health professions from diverse backgrounds. With this support, over 5,000 students have been able to participate in KU's health professions pipeline programs.

In closing, HPNEC's \$600 million recommendation for the existing health professions programs will not only help sustain the expansion of the health workforce supported in recent years, but will also help to ensure the programs are able to fulfill their mission of improving the supply distribution and diversity of health professionals nationwide.

Thank you.

[Written statement by Heidi Chumley follows.]



**TESTIMONY OF THE HEALTH PROFESSIONS AND NURSING
EDUCATION COALITION**

**CONCERNING HRSA'S TITLE VII AND TITLE VIII HEALTH PROFESSIONS
PROGRAMS**

Before the
U.S HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED
AGENCIES
MAY 12, 2010 AT 10:00 AM

By
HEIDI CHUMLEY, M.D.
SENIOR ASSOCIATE DEAN OF MEDICAL EDUCATION
UNIVERSITY OF KANSAS MEDICAL CENTER

Summary:

- The health professions education programs, authorized under Title VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration, **support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce**, filling gaps in the supply of health professionals not met by traditional market forces. They are the only federal programs designed to train providers in interdisciplinary settings to meet the needs to special and underserved populations, as well as increase minority representation in the workforce.
- According to HRSA, **over 30,000 health practitioners would be needed to alleviate existing health professional shortages** and the shortages will only grow as additional Americans seek access to health care services. Combined with faculty shortages across disciplines, racial/ethnic disparities in health care, and a rapidly aging population, these needs strain an already fragile health care system.
- **HPNEC recommends \$600 million in FY 2011 for the existing Title VII and Title VIII programs.** This investment is essential not only to the development and training of tomorrow's health care professionals, but also to our country's efforts to provide needed health care services to the medically underserved. HPNEC also encourages investment in the new health professions programs and responsibilities under the Patient Protection and Affordable Care Act to supplement investment in the existing programs.

**Testimony of the Health Professions and Nursing Education Coalition (HPNEC) Concerning
HRSA's Title VII & VIII Health Professions Programs**

*Submitted for the Record to the House Appropriations Subcommittee on
Labor, Health and Human Services, and Education – May 12, 2010*

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record in support of **\$600 million in fiscal year (FY) 2011 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA)**. HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals, and students dedicated to ensuring the health care workforce is trained to meet the needs of our diverse population.

As you know, the Title VII and VIII health professions and nursing programs are essential components of the nation's health care safety net, bringing health care services to our underserved communities. These programs support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and VIII programs are the only federal programs designed to train providers in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

We are thankful to the Subcommittee for the increases provided for many Title VII and Title VIII programs in the FY 2010 Omnibus Appropriations bill (P.L. 111-117). These investments are crucial to addressing the existing and looming shortages of health care professionals in this country and are key to ensuring the nation's health care professionals are able to care for the medically underserved. The Patient Protection and Affordable Care Act (P.L. 111-148) updated and restructured the existing Title VII and Title VIII programs to improve their efficiency, effectiveness, and accountability, and reauthorized them at funding levels reflective of the health workforce needs of the nation. In addition to reauthorizing the existing health professions programs, the legislation authorizes several new programs and initiatives under Titles VII and VIII designed to mitigate health workforce challenges and expand the scope of the programs to additional fields. HPNEC encourages an investment in these new programs that supplements the support for the core Title VII and Title VIII programs. These investments will be critical to ensuring that the health care workforce can accomplish the goals of health care reform.

We are grateful to President Obama for highlighting the need to strengthen the health professions workforce as a national priority; however, significant strides must still be made to ensure that all Americans have access to the health professionals they need. According to HRSA, an additional 31,000 health practitioners are needed to alleviate existing professional shortages. Combined with faculty shortages across health professions disciplines, racial/ethnic disparities in health care, and a growing, aging population, these needs strain an already fragile health care system. Because of the time required to train health professionals, we must make appropriate investments today to ensure that the Title VII and Title VIII programs are able to continue strengthening the

country's safety net for the health care needs of the medically underserved.

The existing Title VII and Title VIII programs can be considered in seven general categories:

- The purpose of the **Minority and Disadvantaged Health Professionals Training** programs is to improve health care access in underserved areas and the representation of minority and disadvantaged health care providers in the health professions. *Minority Centers of Excellence* support programs that seek to increase the number of minority health professionals through increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The *Health Careers Opportunity Program* seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The *Faculty Loan Repayment and Faculty Fellowship* programs provide incentives for schools to recruit underrepresented minority faculty. The *Scholarships for Disadvantaged Students* make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students.
- The **Primary Care Medicine and Dentistry** programs, including *General Pediatrics*, *General Internal Medicine*, *Family Medicine*, *General Dentistry*, *Pediatric Dentistry*, and *Physician Assistants*, provide for the education and training of primary care physicians, dentists, and physician assistants to improve access and quality of health care in underserved areas. Two-thirds of all Americans interact with a primary care provider every year. Approximately one-half of primary care providers trained through these programs go on to work in underserved areas, compared to 10 percent of those not trained through these programs. The *General Pediatrics*, *General Internal Medicine*, and *Family Medicine* programs provide critical funding for primary care training in community-based settings and have been successful in directing more primary care physicians to work in underserved areas. They support a range of initiatives, including medical student training, residency training, faculty development and the development of academic administrative units. The *General Dentistry* and *Pediatric Dentistry* programs provide grants to dental schools and hospitals to create or expand primary care dental residency training programs, while the *Dental Public Health Residency* programs are vital to the nation's dental public health infrastructure. Recognizing that all primary care is not only provided by physicians, the primary care cluster also provides grants for *Physician Assistant* programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. And finally, the primary care cluster enhances the efforts of osteopathic medical schools to continue to emphasize primary care medicine, health promotion, and disease prevention, and the practice of ambulatory medicine in community-based settings.
- Because much of the nation's health care is delivered in areas far removed from health professions schools, the **Interdisciplinary, Community-Based Linkages** cluster provides support for community-based training of various health professionals. These programs are designed to provide greater flexibility in training and to encourage collaboration between two or more disciplines. These training programs also serve to encourage health professionals to return to such settings after completing their training. The *Area Health Education Centers (AHECs)* provide clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of

academic health centers to these areas. AHECs, which have substantial state and local matching funds, form networks of health-related institutions to provide education services to students, faculty and practitioners. *Geriatric Health Professions* programs support geriatric faculty fellowships, the Geriatric Academic Career Award, and Geriatric Education Centers, which are all designed to bolster the number and quality of health care providers caring for our older generations. Given America's burgeoning aging population, there is a need for specialized training in the diagnosis, treatment, and prevention of disease and other health concerns of older adults. The *Allied Health Project Grants* program represents the only federal effort aimed at supporting new and innovative education programs designed to reduce shortages of allied health professionals and create opportunities in medically underserved and minority areas. Health professions schools use this funding to help establish or expand allied health training programs. The need to address the critical shortage of certain allied health professionals has been acknowledged repeatedly. For example, this shortage has received special attention given past bioterrorism events and efforts to prepare for possible future attacks. The *Graduate Psychology Education Program* provides grants to doctoral, internship and postdoctoral programs in support of interdisciplinary training of psychology students with other health professionals for the provision of mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill, and victims of abuse and trauma, including returning military personnel and their families), especially in rural and urban communities.

- The **Health Professions Workforce Information and Analysis** program provides grants to institutions to collect and analyze data on the health professions workforce to advise future decision-making on the direction of health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed a number of valuable, policy-relevant studies on the distribution and training of health professionals, including the National Sample Survey of Registered Nurses, the nation's most extensive and comprehensive source of statistics on registered nurses.
- The **Public Health Workforce Development** programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The *Public Health Traineeships and Public Health Training Centers* seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. *Preventive Medicine Residencies*, which receive minimal funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. *Dental Public Health Residency* programs are vital to the nation's dental public health infrastructure.
- The **Nursing Workforce Development** programs under Title VIII provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. These programs provide the largest source of federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support to 77,395 nursing students and nurses in FY 2008. Health care entities across the nation are experiencing a crisis in nurse staffing, caused in part by an aging workforce and capacity limitations within the educational system. Each year, nursing schools turn away tens of

thousands of qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. At the same time, the need for nursing services and licensed, registered nurses is expected to increase significantly over the next 20 years. The *Advanced Education Nursing* program awards grants to train a variety of advanced practice nurses, including nurse practitioners, certified nurse-midwives, nurse anesthetists, public health nurses, nurse educators, and nurse administrators. For example, this funding has been instrumental in doubling nurse anesthesia graduates in the last eight years. However, even though the number of graduates doubled, the vacancy rate for nurse anesthetists has remained the same at 12 percent, due to a retiring nursing profession and an aging population requiring more care. *Workforce Diversity* grants support opportunities for nursing education for students from disadvantaged backgrounds through scholarships, stipends, and retention activities. *Nurse Education, Practice, and Retention* grants are awarded to help schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and other health care facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The *Loan Repayment and Scholarship Program* repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds. In return these students are required to work for at least two years of practice in a designated nursing shortage area. The *Comprehensive Geriatric Education* grants are used to train RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, train faculty members, and provide continuing education. The *Nurse Faculty Loan* program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty.

- The loan programs under **Student Financial Assistance** support financially needy and disadvantaged medical and nursing school students in covering the costs of their education. The *Nursing Student Loan* (NSL) program provides loans to undergraduate and graduate nursing students with a preference for those with the greatest financial need. The *Primary Care Loan* (PCL) program provides loans covering the cost of attendance in return for dedicated service in primary care. The *Health Professional Student Loan* (HPSL) program provides loans covering the cost of attendance for financially needy health professions students based on institutional determination. The NSL, PCL, and HPSL programs are funded out of each institution's revolving fund and do not receive federal appropriations. The *Loans for Disadvantaged Students* program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.

These programs work collectively to fulfill their unique, three-pronged mission of improving the supply, diversity, and distribution of the health professions workforce. While HPNEC members are keenly aware of the fiscal pressures facing the Subcommittee, we respectfully urge support for funding of at least **\$600 million** for the Title VII and VIII programs, an investment essential not only to the development and training of tomorrow's health care professionals but also to our nation's efforts to provide needed health care services to underserved and minority communities. We also encourage an investment in the new programs and responsibilities authorized in the Patient Protection and Affordable Care Act to supplement the investment in the existing core programs. We greatly appreciate the support of the Subcommittee and look forward to working with Members of Congress to reinvest in the health professions programs in FY 2011 and into the future.

Heidi S. Chumley, MD
 Associate Professor, with Tenure, Department of Family Medicine
 University of Kansas, School of Medicine
 3901 Rainbow Blvd, Mail Stop 4010, Kansas City, KS, 66160
 Phone: (913) 588-7201 Email: hchumley@kumc.edu

Current position/responsibilities: Senior Associate Dean for Medical Education

- Develop and implement a solid vision for medical student education
- Supervise the Associate Deans of Medical Education, Admissions, Student Affairs, Cultural Enhancement and Diversity and Rural Medicine
- Develop and enhance initiative to address physician workforce issues in Kansas
- Address accreditation issues for the School of Medicine
- Manage a 3.5 million dollar budget
- Member, Executive Vice Chancellor's and Executive Dean's leadership teams

Education and Training:

| Institution and Location | Degree | Year | Field of Study |
|---|------------|------|-------------------|
| Abilene Christian University; Abilene, TX | BA | 1992 | Biochemistry |
| Univ of TX HSC-San Antonio; San Antonio, TX | MD | 1996 | Medicine |
| Univ of TX HSC-San Antonio; San Antonio, TX | Residency | 1999 | Family Medicine |
| Academic Leadership Fellowship; UTHSC-SA, San Antonio, TX | Fellowship | 2002 | Academic Medicine |

Recent Professional Appointments:

| | | |
|--------------|---|--------------------------|
| 2008-present | Senior Associate Dean for Medical Education | Kansas University SOM |
| 2006-2008 | Associate Chair, Undergraduate Medical Ed. | Kansas University SOM |
| 2004-2008 | Director of Predoctoral Education | Kansas University SOM |
| 2003-2004 | Associate Predoctoral Director | UTHSC-SA/Family Practice |
| 1999-2001 | Assistant Residency Director | UTHSC-SA/Family Practice |

Recent Publications:

- Chumley H, et al. The National Family Medicine Clerkship Curriculum. www.stfm.org
- Delzell JE, Chumley H, Webb R, Chakrabarti S, Relan A. Information-gathering patterns associated with higher rates of diagnostic error. *Adv. in Health Sciences Ed.* (in press)
- Rouf E, Chumley H and Dobbie A. Electronic health records in outpatient clinics: perspectives of third-year medical students. *BMC Medical Education*, 2008, 8:13 (31Mar2008).
- Chumley H & Kim S. Proceedings from the 2007 Family Medicine Predoctoral Conference. *Teaching and Learning in Medicine*, 2007;18(4).
- Chumley H & Steele D, Editors. Proceedings from the 2006 Family Medicine Predoctoral Conference. *Teaching and Learning in Medicine*, 2006;18(4):356-361.
- Chumley HS, Dobbie A, Pollock M, Delzell JE jr. Teaching medical students to prioritize preventive services. *Family Medicine*. 2006;38(10):696-699.
- Chumley H, Dobbie A, Delzell J. Case-based exercises fail to improve medical students' information management skills: a controlled trial. *BMC Medical Education*. 2006;6:14.
- Chumley H, Olney C, Usatine R, Dobbie A. A short transitional course can help medical students prepare for clinical learning. *Family Medicine*. 2005;37(7):496-501.
- AAMC Task Force on the clinical skills education of medical students. Recommendations for Clinical Skills Curricula for Undergraduate Medical Education, Association of American Medical Colleges, Washington, D.C. 2005.

Mr. OBEY. Thank you. Appreciate it.
Lori J. Heim, American Academy of Family Physicians.

WEDNESDAY, MAY 12, 2010.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

WITNESS

LORI J. HEIM, MD, PRESIDENT, AMERICAN ACADEMY OF FAMILY PHYSICIANS

Dr. HEIM. Good morning, Chairman Obey and members of the Subcommittee. I am Dr. Lori Heim, family physician from Vass, North Carolina. As the President of the American Academy of Family Physicians, representing 94,700 family doctors, residents, and medical students, I congratulate the Congress on the enactment of the Patient Protection and Affordable Care Act.

In order for a successful implementation of that health care reform, I urge you, despite what you said, Chairman, to increase the Federal investment in primary care workforce. Despite the consensus that good primary care is essential for genuine health care reform, 65 million Americans—that is about one in five—live in primary care shortage areas.

Not only do we have shortages in primary care physicians in practice, but the medical education pipeline is now only producing 22.6 primary care physicians, down from 33 percent a decade ago. As a result, we have fewer primary care physicians being trained to care for the newly insured.

Health reforms include a number of provisions to increase the workforce, including the vital Primary Care Medicine Grants authorized through Title VII. We believe a minimum of \$600 million for all of Title VII programs is needed. We also urge the Committee to provide \$170 million for Title VII Section 747 primary care training and enhancement programs.

Physician shortages are particularly hard on rural Americans, as they face more barriers to care than their urban or suburban areas. Family physicians provide the majority of the care for America's underserved and rural populations, so we were very pleased with the new Rural Physician Training Grants authorized by health reform. We request that you fully fund the Title VII Rural Physician Training Grants.

The AAFP supported the authorization of the innovative Teaching Health Centers Program to train primary care residents in non-hospital settings, which is where the care is delivered. However, if this program is going to be effective, there must be grants for planning. We recommend the Committee appropriate the full authorized amounts for the Teaching Health Centers Developmental Grants of \$50 million for fiscal year 2011.

Another significant barrier to the production of primary care physicians is the huge student debt that they have. The National Health Service Corps has long provided debt relief to primary care physicians and has helped to reduce the health disparities. We urge that the Corps receive \$414.1 million in fiscal year 2011.

The AAFP commends Congress for authorizing the Primary Care Extension Program within the Agency for Health Care Research

and Quality, as small primary care practices need the kind of support that was offered by the Federal Cooperation Extension Services to implement innovative and best practices. This new program will assist primary care providers to transform their practices using effective evidence-based therapies and techniques in their practices. The AAFP recommends the Committee provide \$731 million for AHRQ to provide the funding requested in the President's budget, as well as the important new Primary Care Extension Program authorized by the health reform law at \$120 million.

Thank you very much for the opportunity, sir.

[Written statement by Lori Heim follows:]



AMERICAN ACADEMY OF
FAMILY PHYSICIANS
STRONG MEDICINE FOR AMERICA

Statement of the American Academy of Family Physicians

Before the Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies of the
House Appropriations Committee
U.S. House of Representatives

The Need for Federal Investment in Primary Care:
How HRSA and AHRQ Can Address Physician Shortages and
Improve Access to Quality, Affordable Health Care

Presented By
Lori Heim, MD, FAAFP, Vass, North Carolina
President, American Academy of Family Physicians

May 12, 2010 – 10:00 AM

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Lori Heim, MD, FAAFP, President
American Academy of Family Physicians
 Public Witness Testimony for the House Appropriations
 Labor/HHS/Education Subcommittee – May 12, 2010

As one of the largest national medical organizations, representing 94,700 family physicians, residents, and medical students, the AAFP recommends that the House Appropriations Subcommittee on Labor, Health and Human Services, and Education continue its commitment to Title VII in fiscal year 2011 and increase funding for other key Health Resources and Services Administration programs to allow health reform to succeed. We also recommend increased funding for the Agency for Healthcare Research and Quality to provide better health care all.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

The *Patient Protection and Affordable Care Act* (PL 111-148) holds the promise of health security for Americans and moves us toward genuine health system reform, but it will require the support of this Committee to invest in the necessary primary care physician workforce. Primary care physicians will serve as a strong foundation for a more efficient and effective health care system. We are pleased that the health reform law reauthorizes the Title VII health professions programs including the grants for the education and training of primary care physicians under Title VII, Section 747.

Workforce shortages

Successful implementation of health reform requires an investment to strengthen our nation's primary care workforce. The current national primary care physician workforce of just over 200,000 is estimated to be 8,000-10,000 lower than projected demand based on adjusted average population utilization patterns, according to the Robert Graham Center for Policy Studies in Family Medicine and Primary Care. However, distribution is not equitable leaving many areas with physician shortages, especially in rural and underserved communities with measurable social deprivation.

In the coming years, medical services utilization is likely to rise given the increasing and aging population as well as the insured status of more of the populace. Those demographic trends will cause primary care physician shortages to worsen. By 2025, the current downturn in primary care physician production is expected to yield a workforce 28.5 percent below need based on current practice models or 50 percent below the level needed to provide all Americans with a patient-centered medical home.

The recently enacted health reform legislation includes a number of provisions to increase the primary care workforce. It amends and expands many of the existing health workforce programs authorized under Title VII (health professions) and makes a number of changes to Medicare graduate medical education (GME) payments to teaching hospitals, in part to encourage the training of more primary care physicians. The new law also establishes a national commission to study projected health workforce needs and make appropriate recommendations. Increasing the level of federal funding

for primary care training would reinvigorate medical education, residency programs, as well as academic and faculty development in primary care to prepare physicians to support the patient centered medical home.

This Committee has demonstrated its commitment to a strong primary care workforce by doubling the appropriation for training under Title VII Section 747 of the Public Health Services Act in the *American Recovery and Reinvestment Act of 2009* (PL 111-5) and calling for increased appropriations for the current fiscal year.

The AAFP urges the Committee to provide a FY 2011 appropriation of \$170 million for the Title VII Section 747 Primary Care Training and Enhancement and the Integrative Academic Administrative Units programs as authorized by the *Patient Protection and Affordable Care Act*. We also recommend an appropriation of at least \$600 million for all of the Health Professions Training Programs authorized under Title VII of the Public Health Services Act.

Rural Health Needs

Physician shortages are harder for Americans in rural areas who face more barriers to care than those in urban and suburban areas. Rural residents also struggle with the higher rates of illness associated with lower socioeconomic status.

We were pleased that Title VII, Section 749B, the "Rural Physician Training Grants" program, was enacted to help medical schools to recruit students most likely to practice medicine in underserved rural communities, provide rural-focused training and experience, and increase the number of recent medical school graduates who practice in underserved rural communities.

Family physicians provide the majority of care for America's underserved and rural populations.¹ Despite efforts to meet scarcities in rural areas, the shortage of primary care physicians continues. Studies, whether they be based on the demand to hire physicians by hospitals and physician groups or based on the number of individuals per physician in a rural area, all indicate a need for additional physicians in rural areas.

HRSA's Office of Rural Health administers a number of programs to improve health care services to the quarter of our population residing in rural communities.

The AAFP requests that the Committee provide \$4 million in FY 2011 for Title VII Section 749B Rural Physician Training Grants. The AAFP also encourages the Committee to provide \$176 million for the programs administered by HRSA's Office of Rural Health to address the many unique health service needs of rural communities.

¹ Hing E, Burt CW. Characteristics of office-based physicians and their practices: United States, 2003–04. Series 13, No. 164. Hyattsville, MD: National Center for Health Statistics. 2007.

Teaching Health Centers

The AAFP supported the authorization in the health reform legislation of the innovative Teaching Health Centers program under Title VII Section 749A to increase primary care physician training capacity. Federal financing of graduate medical education has led to training which occurs mainly in hospital inpatient settings in spite of the fact that most patient care is delivered outside of hospitals in ambulatory settings across the nation. As a result, we have been training physicians using experiences which poorly prepare them to practice primary care in the community outside the hospital.

The Teaching Health Center program will train primary care residents in non-hospital settings where most primary care is delivered. A Teaching Health Center can be any community based ambulatory care setting that operates a primary care residency program including Federally Qualified Health Centers or Federally Qualified Health Centers Look Alikes, Rural Health Clinics, Community Mental Health Centers, a Health Center operated by the Indian Health Service, or a center receiving Title X grants.

We were pleased that the *Patient Protection and Affordable Care Act* authorized a mandatory appropriations trust fund of \$230 million over five years to fund the operations of Teaching Health Centers. However, if this program is to be effective, there must be funds for the planning grants to establish newly accredited or expanded primary care residency programs.

The AAFP recommends that the Committee appropriate the full authorized amount for the new Title VII Teaching Health Centers development grants of \$50 million for fiscal year 2011.

National Health Service Corps

The National Health Services Corps (NHSC) has long served to provide access to health care to underserved Americans and offer incentives for practitioners to enter primary care. NHSC also provides important student debt relief for new physicians.

Student debt was found to be a significant barrier to the production of primary care physicians by a report published in March 2009, by the Graham Center with the support of the Macy Foundation². The AAFP supports the work of the NHSC toward the goal of full funding for the training of the health workforce and zero disparities in health care. We recognize that this Committee provided an increase for the NHSC in the *American Recovery and Reinvestment Act*, and we commend Congress for increasing the authorization level for the NHSC in the new health reform law.

The AAFP recommends that the National Health Service Corps receive \$414.1 million in FY 2011 as authorized in the *Patient Protection and Affordable Care Act* which makes \$290 million of that amount available from a fund created in Section 10503.

² The Robert Graham Center. *Specialty and Geographic Distribution of the Physician Workforce: What Influences Medical Student & Resident Choices?* March 2, 2009.

Workforce Commission

The AAFP has called for a commission on national health workforce issues which represents the multiple stakeholders and reports to Congress and the Executive Branch as appropriate. We were pleased that the health reform bill established a National Health Care Workforce Commission to provide “analysis of, and recommendations for, eliminating the barriers to entering and staying in primary care, including provider compensation.” We also recognize the importance of the National Center for Health Care Workforce Analysis as well as State and Regional Centers for such analysis. The legislation authorized such sums as necessary to establish the Commission as well as \$8 million in planning grants and \$150 million for implementation grants. The National Center was authorized at \$7.5 million annually and the State and Regional Centers were authorized at \$4.5 million annually.

The AAFP recommends that the Committee fully fund the National Health Care Workforce Commission, the National and State and Regional Centers for Health Care Workforce Analysis in FY 2011.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

To assure the success of health reform, we must also focus on paying for quality rather than quantity. The mission of the Agency for Healthcare Research and Quality (AHRQ)—to improve the quality, safety, efficiency, and effectiveness of health care for all Americans—closely mirrors the AAFP’s own mission. AHRQ is a small agency with a huge responsibility for research to support clinical decision-making, reduce costs, advance patient safety, decrease medical errors and improve health care quality and access. Family physicians recognize that AHRQ has a critical role to play in patient-centered, comparative effectiveness research.

Primary Care Extension Program

The AAFP commends the Congress for authorizing in the *Patient Protection and Affordable Care Act* a Primary Care Extension Program to be administered by AHRQ to provide support and assistance to primary care providers about evidence-based therapies and techniques so that providers can incorporate them into their practice. Family physicians Kevin Grumbach, MD and James W. Mold, MD, MPH recognized that small primary care practices need a similar kind of support offered by the federal government to farms by the Cooperative Extension Service to implement innovation and best practices.³

The AAFP requests that the Committee provide \$731 million for AHRQ in FY 2011 to provide for the funding requested by the President’s budget request of \$611 million as well as the important new Primary Care Extension program authorized by the health reform law at \$120 million.

³ Grumbach K, Mold JW. A Health Care Cooperative Extension Services: Transforming Primary Care and Community Health. *JAMA*. June 24, 2009—Vol 301, No. 24.



Lori J. Heim, MD, FAFP
President
American Academy of Family Physicians

Lori J. Heim, MD, FAFP, is president of the American Academy of Family Physicians. Heim was elected to the board of directors in September 2005 by the AAFP's governing body, the Congress of Delegates and again in 2008 as the President-elect. The AAFP represents more than 94,600 physicians and medical students nationwide.

As president of the AAFP, Heim advocates on behalf of family physicians and patients nationwide to inspire positive change in the U.S. health care system. A practicing family physician for 21 years, Heim currently serves as a hospitalist at Scotland Memorial Hospital in Laurinburg, North Carolina, where she manages the inpatient care of adult patients referred by primary care physicians in the community. Hospitalists bridge the gap between hospitalized patients and their primary care doctors to ensure continuity of care. Previously, she was in private practice in Pinehurst, North Carolina.

A member of the AAFP since 1985, Heim served as a delegate to the AAFP Congress of Delegates from 2000 to 2004. She served on the Commission on Health Care Services and on the Task Force of Linkages to Practice Improvement. In addition, she held the offices of president, vice president and member of the board of directors of the Uniformed Services Academy of Family Physicians. Heim joined the North Carolina Academy of Family Physicians when she retired from the U.S. Air Force in 2007.

Heim also served on the board of managers of TransforMED LLC, a for-profit wholly-owned subsidiary of the AAFP that is focused on helping primary care medical practices adopt the patient-centered medical home model of care. In this role, Heim worked with other members of the board of managers to approve and oversee the TransforMED operating budget, as well as goals and performance measures to assure consistency with the AAFP's budgeted capital contributions to the new business entity.

Heim earned her bachelor's degree with honors from Portland State University, Oregon, and was then commissioned in the U.S. Air Force and earned her medical degree at the Uniformed Services University of the Health Sciences, Bethesda, Md. She completed her residency at the Family Medicine Residency, Andrews Air Force Base, Md. She then completed a fellowship in faculty development and research from the University of North Carolina at Chapel Hill. Heim is board certified by the American Board of Family Medicine and has the AAFP Degree of Fellow, an earned degree awarded to family physicians for distinguished service and continuing medical education.

Heim's appointments with the Air Force included staff physician, clinic chief, residency director, assistant professor, university health center director, chief of the medical staff and commander. She was stationed internationally in Turkey and domestically in Washington, DC, Florida, North Carolina and Washington state. She retired as a colonel from the Air Force after 25 years of service.

Heim has lectured worldwide and her work has been published in peer-reviewed journals. She participated in humanitarian missions and volunteered in medical clinics in underserved communities. She has received numerous decorations including the Air Force Meritorious Medal, Defense Meritorious Service Medal, Air Force Commendation Medal and the Air Force Achievement Medal. Her awards include the Joint Meritorious Unit Award, Air Force Outstanding Unit Award, Humanitarian Service Award and the National Defense Service Award.

Mr. OBEY. Thank you. Again, let me simply say that I agree with everything you said. The problem is there is no way I can get there because, in negotiations over the budget resolution right now, for instance, one of the offers on the table, in order to get people who are reluctant to vote for it to actually do so, one of the offers was to reduce domestic appropriations by \$110 billion over the next five years. That is not deep enough for some of our brethren.

So I would love to provide the dollars you are talking about. We do not have the votes for it because we have to live under budget ceilings and, as I said earlier, there are a whole lot of people who are very comfortable at reducing the deficit by cutting this portion of the budget, but not in cutting the portions of the budget that have been treated much more gingerly the last ten years.

But thank you for coming.

Dr. HEIM. Thank you. And we will help take that message forward because, otherwise, without the workforce, we will not be able to take care of the people.

Mr. OBEY. You are absolutely right.

Next, Wayne Riley, Association of Minority Health Professions Schools.

WEDNESDAY, MAY 12, 2010.

**HEALTH RESOURCES AND SERVICES
ADMINISTRATION—TITLE VII**

WITNESS

WAYNE J. RILEY, MD, MPH, CHAIRMAN, BOARD OF DIRECTORS, ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS, INC.

Dr. RILEY. Good morning, Mr. Chairman, members of the Subcommittee. It is my pleasure to be here today. My name is Wayne Riley, President and Chief Executive Officer of Meharry Medical College, Nashville, Tennessee. I am here today in my role as Chair of the Association of Minority Health Professions Schools. AMHPS, as it is called, represents 12 of the Nation's superb HBCU academic health science centers. We train graduates in dentistry, pharmacy, medicine, and veterinary medicine. Mr. Chairman, these institutions are indeed national treasures.

We applaud the passage of health care reform, as some of my colleagues have already mentioned, but we do want to alert the Committee that, with the passage of health care reform, there are looming shortages of health professionals to take care of Americans. We are particularly concerned about the shortage among minority groups. For example, although African-Americans represent 13 percent of the Nation's population, only 3 percent of health care professionals are African-American. The similar statistics are evident in Latino and Native American and Asian Pacific Islanders as well.

Now, sometimes I get the question: Why are you guys always up here asking for help? Well, it is simple. Minority-serving institutions do not have the big endowments; we do not have big fat donors that give us millions of dollars to do our work. But we are private institutions with a very public mission, and we take that mission very seriously. So much so that our institutions are among the leaders in producing primary care physicians.

Next week, I will graduate a class of Meharry physicians, of which over 50 percent are going into primary care fields, the kinds of doctors our Nation needs.

So the programs that this Subcommittee has jurisdiction over are very important to us. The first being Title VII Health Profession Training. As you know, there were some cuts between 2006 and here, cuts anywhere from 45 to 90 percent in COE and HCOP. Those cuts have partially been restored, and we appreciate your leadership, Mr. Obey, on restoring some of this. However, we do request a consideration of the Subcommittee and the Committee and the Congress to restore the program to about the \$300 million level, which would add an incremental increase of \$33 million to \$35 million respectively, in Title VII.

The other program particularly germane to our mission is the National Center for Research Resources. That is the Extramural Facilities Program which helps to beef up our laboratories and clinical facilities on our campuses. We are recommending \$50 million for extramural facilities construction and we remind the Subcommittee that the first 25 percent of such appropriations are earmarked or set aside, rather, for institutions of emerging excellence like the 12 I represent.

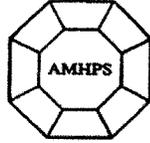
Also want to highlight the work of the Research Careers and Minority Institutions Program, again, that allows us to focus our work there.

One of the great byproducts of health care reform, Mr. Chairman, is the fact that we now have a new institute, the National Institute of Minority Health and Health Disparities, which was elevated through the landmark legislation. This is outstanding news, but we urge the Committee to fund it at an institute level of approximately \$500 million given the fact that it has been given significantly enhanced authority and power over Minority and Health Disparities work.

Mr. Chairman, we also ask consideration to increase the HBGI program, which trains doctoral students at our institutions.

We appreciate the work of this Committee. Mr. Chairman, we salute you for your distinguished service to Congress and our Nation in the 7th Congressional District of Wisconsin. You have been a champion of these programs and we salute you. Thank you, Mr. Chairman.

[Written statement by Wayne J. Riley follows:]



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CHAIRMAN, BOARD OF DIRECTORS
ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS
ATLANTA, GEORGIA**

**&
PRESIDENT & CHIEF EXECUTIVE OFFICER
PROFESSOR OF INTERNAL MEDICINE
MEHARRY MEDICAL COLLEGE
NASHVILLE, TENNESSEE**

MAY 12TH, 2010, 10:00 AM

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH
AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**

MEMBERS

Charles Drew University
of Medicine and Science
Los Angeles, California

Florida A & M University
College of Pharmacy
& Pharmaceutical Sciences
Tallahassee, Florida

Hampton University
School of Pharmacy
Hampton, Virginia

Howard University
College of Medicine
College of Pharmacy, Nursing
& Allied Health Sciences
College of Dentistry
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Meharry Medical College
School of Medicine &
School of Dentistry
Nashville, Tennessee

Morehouse School of Medicine
Atlanta, Georgia

Texas Southern University
College of Pharmacy
& Health Sciences
Houston, Texas

Tuskegee University
College of Veterinary
Medicine, Nursing
& Allied Health
Tuskegee, Alabama

Xavier University of Louisiana
College of Pharmacy
New Orleans, Louisiana

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SUMMARY OF FISCAL YEAR 2011 RECOMMENDATIONS:

**1) \$300 MILLION FOR THE TITLE VII HEALTH PROFESSIONS
TRAINING PROGRAMS, INCLUDING:**

- \$33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.
- \$35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.

**2) SUPPORT FOR THE NATIONAL CENTER FOR RESEARCH
RESOURCES.**

- 15% INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.
- \$50 MILLION FOR EXTRAMURAL FACILITIES CONSTRUCTION.

**3) \$500 MILLION FOR THE NATIONAL INSTITUTES OF HEALTH'S
NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH
DISPARITIES.**

**4) \$100 MILLION FOR THE DEPARTMENT OF HEALTH AND
HUMAN SERVICES' OFFICE OF MINORITY HEALTH.**

**5) \$100 MILLION FOR THE DEPARTMENT OF EDUCATION'S
STRENGTHENING HISTORICALLY BLACK GRADUATE
INSTITUTIONS PROGRAM.**

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wayne J. Riley, Chair of the Board of the Association of Minority Health Professions Schools (AMHPS) and the President and Chief Executive Officer of Meharry Medical College. AMHPS, established in 1976, is a consortium of our nation's twelve (12) historically black medical, dental, pharmacy, and veterinary schools. The members are two dental schools at Howard University and Meharry Medical College; four schools of medicine at The Charles Drew University, Howard University, Meharry Medical College, and Morehouse School of Medicine; five schools of pharmacy at Florida A&M University, Hampton University, Howard University, Texas Southern University, and Xavier University; and one school of veterinary medicine at Tuskegee University. As a medical doctor and throughout my entire career, I have seen firsthand the importance of minority health professions institutions and the federal support which they receive, including the Title VII Health Professions Training programs, funding from the National Institutes of Health, and programs at the Department of Education.

Mr. Chairman, after the historic passage of the health reform bill, which AMHPS supported, the nation's supply of health professionals, especially minority health professionals who disproportionately tend to serve more in underserved areas, will be in even more demand. The minority health professions institutions and their major sources of funding address a critical, national need. Even before the passage of health reform, persistent and severe staffing shortages existed in a number of the health professions, and chronic shortages existed for all of the health professions in our nation's most medically underserved communities. The need to produce more health professionals will only increase as more of our fellow citizens have access to health care. Furthermore, even after the landmark passage of health reform, it is important to note that our nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 13% of the U.S. population, only 2-3% of the nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help AMHPS continue our efforts to provide our nation with quality health professionals and close our nation's health disparity gap.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "*The Rationale for Diversity in the Health Professions: A Review of the Evidence*," found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. **Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities, and 3) treat low-income patients.**

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Title VII Diversity Cluster of the Health Professions Training Programs: As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic

distribution, and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students who practice disproportionately in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion. Mr. Chairman, I am a product of one of the Title VII programs—the Faculty Loan Repayment Program—and now I am privileged to lead an institution dedicated to eliminating health disparities.

In FY 05, the funding for the Title VII Health Professions Training programs was robust, allowing the nation's health professions schools to make a contribution to increasing the number of and diversity in the health professions. In FY 06, these programs received a dramatic cut, including a 64.7% reduction for the Minority Centers of Excellence (COE) program and an 88.9% decrease for the Health Careers Opportunities Program (HCOP). Overall, the programs affecting diversity in the health professions received a 45.8% reduction in FY 06. Since then, COE, HCOP, and the other diversity programs have made some increases—and AMHPS is grateful for this Subcommittee's investment in health professions training; but compared to FY 05, COE is currently still down more than 28% compared to FY 05 and HCOP is still down by nearly 38% compared to FY 05. In FY11, funding for the Title VII Health Professions Training programs must be restored to the FY05 level of funding, \$300 million, with COE funded at \$33.609 million and HCOP funded at \$35.647 million. (See chart for more information.) Mr. Chairman, with the emphasis renewed on the demand for health professionals that our new health system will require, we must allow the funding for COE, HCOP, and the diversity programs of Title VII to receive more growth.

**Title VII Health Professions Programs
FY 2011 Funding**

| | (\$ in thousands) | | | | | | | | |
|--|-------------------|------------------|----------------------------------|------------------|------------------|------------------|------------------|----------------------------------|---------------------------------|
| | FY 2005 Final | FY 2006 Final | Percent Change (vs. FY 05) | FY 2007 Final | FY 2008 Final | FY 2009 Final | FY 2010 Final | FY 2011 President's Budget | Percent Change (v. FY 10) |
| Centers of Excellence | 33,609 | 11,880 | -64.7% | 11,880 | 12,773 | 20,602 | 24,602 | 24,062 | 0% |
| Health Careers Opportunity Program | 35,647 | 3,957 | -88.9% | 3,957 | 9,825 | 19,133 | 22,133 | 22,133 | 0% |
| Faculty Loan Repayment | 1,302 | 1,288 | -1.0% | 1,288 | 1,266 | 1,266 | 1,266 | 1,266 | 0% |
| Scholarships for Disadvantaged Students | 47,128 | 46,657 | -1.0% | 46,657 | 45,842 | 45,842 | 49,342 | 49,342 | 0% |
| Total, Diversity | 117,686 | 63,786 | -45.8% | 63,786 | 69,706 | 86,843 | 97,343 | 97,343 | 0% |

Minority Centers of Excellence: COE focuses on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues, and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" COEs. *For FY11, We recommend a funding level of \$33.6 million for COEs.*

Health Careers Opportunity Program (HCOP): HCOP provides grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health

professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. *For FY11, we recommend a funding level of \$35.6 million for HCOPs.*

NATIONAL INSTITUTES OF HEALTH (NIH):

Extramural Facilities Program at NCRR: Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH, it is critical that our nation's research infrastructure remain strong. The Extramural Facility Construction program at the National Center for Research Resources (NCRR) has not been funded in recent years, but there was two year funding in American Recovery and Reinvestment Act. It is important to note that the law also includes a 25% set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to \$50 million. We strongly support this provision of the authorizing legislation, because it is necessary for our minority health professions training schools to increase their capacity to do research to narrow the health disparities gap. *In FY11, please provide a funding appropriation of at least \$50 million for extramural facilities.*

Research Centers at Minority Institutions at NCRR: The Research Centers at Minority Institutions program (RCMI) at NCRR has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. It is important to note that this program has been helpful to our institutions as we prepare ourselves to be partners for the effective and heralded Clinical and Translational Science Awards (CTSA). Therefore, *the funding for this important program must grow at the same rate as the NCRR's budget in FY11.*

National Institute on Minority Health and Health Disparities: The National Institute on Minority Health and Health Disparities (NIMHD), recently elevated in the health reform legislation, is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Research Endowment program and the Minority Centers of Excellence program. *For FY11, we recommend a funding level of \$500 million for the NIMHD.*

HHS OFFICE OF THE SECRETARY

HHS Office of Minority Health: The specific initiatives at OMH, which have become more central to HHS' mission after the passage of health reform, include:

- assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals;

- assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers;
- supporting conferences for high school and undergraduate students to interest them in health careers; and
- supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH, now that has been codified in law thanks to the health reform legislation, has the potential to play a critical and coordinating role in addressing health disparities. *For FY11, we recommend a funding level of \$100 million for the OMH.*

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions Program: The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to AMHPS. This program's funding is used to

- enhance educational capabilities,
- establish and strengthen program development offices,
- initiate endowment campaigns,
- and support numerous other institutional development activities.

This is a program helpful in producing the next generation of minority professionals with advanced graduate degrees. To become eligible, an institution must be named so in law. The HBGI institutions already participating in the program are held harmless at their current funding level so that they have stability in planning their annual budgets. However, the addition of new institutions to the program in recent years calls for a surge in the funding so that new institutions can receive minimum grants and those already participating can receive a much needed cost of living increase. It is also important to note that while many HBCUs, especially undergrads, benefit from the more popular Strengthening HBCUs program; HBGI receives less notoriety but has just as strong an impact on black professionals receiving advanced degrees. *In FY11, an appropriation of \$100 million for HBGI is suggested to continue the vital support the institutions currently competing in this program as well as those which were recently added.*

CLOSING

Mr. Chairman, please allow me to express my appreciation to you for your distinguished service to our nation and the 7th Congressional District of Wisconsin. Your chairmanship of this Subcommittee and the Full Committee has brought our nation much needed stability. I also commend your fellow Subcommittee members, Representatives Jackson and Lee, for their efforts on behalf of minority health. With your continued help and support, AMHPS's member institutions will help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze, stifle, or stymie the institutions and programs that have been **proven to work**. If this subcommittee will give us the tools I described above, we will continue to work towards the goal of eliminating that disparity everyday. Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.



Wayne Joseph Riley, M.D., MPH, MBA, MACP is the 10th President and Chief Executive Officer of Meharry Medical College in Nashville, Tennessee and began his tenure on January 1, 2007.

Previously, he served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine (BCM) in Houston, Texas. He was the first African-American corporate officer in Baylor's history and reported directly to the president and chief executive officer. He earned his Bachelor of Arts (B.A.) degree in anthropology from Yale University in New Haven, Conn., Master of Public Health (M.P.H.) degree in health systems management from the Tulane University School of Public Health and Tropical Medicine in New Orleans, and Doctor of Medicine (M.D.) degree from the Morehouse School of Medicine in Atlanta. In May 2002, he earned the Master of Business Administration (M.B.A.) degree from Rice University's Jesse H. Jones Graduate School of Management's (JGSM) MBA for Executives program.

Under Dr. Riley's leadership and during his tenure, Meharry Medical College has made significant strides in securing philanthropic support, receiving increased National Institutes of Health (NIH) funding, enhancing clinical and academic programs, and increasing national, community and civic engagement. Notable achievements include: reaffirmation of accreditation by the Southern Association of Colleges and Schools and the American Dental Association; the first, ever, accreditation for the Master's degree program in Public Health by the Council for Education for Public Health (CEPH); receipt of an **\$18 million** gift from the Robert Wood Johnson Foundation (including a one-time, \$9 million gift to the endowment making it the largest endowment gift in the College's history) to establish the Robert Wood Johnson Foundation Center for Health Policy at Meharry; the establishment of three U.S. Department of Veterans Affairs outpatient clinics, including the first-ever VA Primary Care Clinic on the campus of a historically black academic health science center, and a specialized Women Veterans Health Clinic, and a partnership with Vanderbilt University to participate in the NIH's Clinical Translational Research Center (CTSA) award; a **\$21 million** NIH award to establish the Meharry Translational Research Center (MeTRC); completion of a **\$4.2 million** dollar renovation of the Meharry Biomedical Sciences Library; and multiple other capital improvements to enhance the teaching and learning environment.

An academic General Internist by training, Dr. Riley is licensed to practice medicine in the states of Tennessee, Texas, Louisiana and Georgia and is board certified in Internal Medicine. He was recently appointed to the newly established Health, Labor and Education Advisory Council for the Federal Reserve Bank of Atlanta and has met with and advised the Obama administration on health reforms proposals. He also serves on the National Advisory Council on Minority Health and Health Disparities (NCMHD) of the National Institutes of Health (NIH).

In 2007, he was inducted into Alpha Omega Alpha (AOA), the nation's only honor medical society and just this past May he was awarded Mastership in the 126,000 member

American College of Physician, an honor bestowed on only approximately 650 physicians and only upon 12 African American physicians. Most recently, Dr. Riley has been elected to membership in the prestigious Society of Medical Administrators. Formed in 1909 as the Medical Superintendents Club, a small group who met annually in New York City to discuss hospital administration – membership was originally limited to 25 individuals, but today, has only 50 members who hold management and leadership responsibilities at major health related institutions, organizations and academic health science centers.

Mr. OBEY. Thank you much.
Next, Debbie Hatmaker, American Nurses Association.

WEDNESDAY, MAY 12, 2010.

**HEALTH RESOURCES AND SERVICES ADMINISTRATION
NURSING PROGRAMS**

WITNESS

**DEBBIE HATMAKER, PHD, RN-BC, SANE-A, FIRST VICE PRESIDENT,
BOARD OF DIRECTORS, AMERICAN NURSES ASSOCIATION**

Ms. HATMAKER. Good morning, Mr. Chairman, distinguished members of the Subcommittee and congressional staff. I am Debbie Dawson Hatmaker. I am here as First Vice President of the American Nurses Association, the largest nursing organization in the Country that represents the interest of the Nation's 3.1 million registered nurses. I have been an RN for 31 years, practicing in a variety of settings, and it is an honor to be with you today to talk about funding for the Title VIII programs.

ANA appreciates the continued support of the Subcommittee, but we remain concerned that Title VIII funding levels have been insufficient to address the growing nursing shortage. In preparation for the implementation of health reform initiatives which ANA strongly supported, we believe there will be even greater demand for nurses, deeming funding even more essential. ANA asks you to meet today's shortage with a relatively modest investment of \$267.3 million in Title VIII programs.

Registered nurses are fundamental to the critical shift that will occur in health services delivery. Title VIII programs recruit new nurses into the profession, promote career advancement, and improve patient care delivery. These programs also direct RNs into areas with the greatest need, including public health, community health centers, and disproportionate share hospitals.

Today, the nursing shortage continues to impact patient care. HRSA released projections that the Nation's nursing shortage would grow more than one million nurses by the year 2020, and that all 50 States would experience a shortage of nurses to varying degrees by the year 2015. The U.S. must graduate approximately 90 percent more nurses to meet this demand.

This growing shortage is already having a real impact on the ability to provide quality care. A study in the Journal Medical Care provides new evidence of the economic value of appropriate RN staffing. The findings demonstrate that as nursing staffing levels increase, patient risk of complications and hospitalization stays decrease, resulting in medical cost savings, improved national productivity, and lives saved. The study suggests that adding 133,000 RNs to the acute care hospital workforce would save 5,900 lives per year. These are not just numbers; these are real avoidable deaths.

In order to meet our Nation's health care needs, an integrated national health care workforce must be put into action. The ability of advanced practice registered nurses to provide high quality, cost-effective care has been widely recognized. Title VIII funds more than 60 percent of U.S. nurse practitioner education programs and assists 83 percent of nurse midwifery programs. Over 45 percent of

the nurse anesthesia graduates supported by this program go on to practice in medically underserved communities.

A study published in the Journal of Rural Health showed that 80 percent of the nurse practitioners who attended a program supported by Title VIII chose to work in a medically underserved or health profession shortage area after graduation.

As an administrator of a clinical nursing program, I experience the difficulty in finding clinical sites for nursing students. One way to combat this problem is to support nurse managed health clinics. With more than 250 clinics reporting over 2.5 million annual client encounters, these clinics also serve as sites for nursing education. Led by advanced practice nurses, the nurse managed care model is especially effective in disease prevention, early detection, and management of chronic conditions.

ANA thanks you for the opportunity, Mr. Chairman, to testify and appreciates your commitment to nursing. We urge you to fund the fiscal year 2011 Title VIII nursing programs at \$267.3 million. Thank you so much.

[Written statement by Debbie Hatmaker follows:]



**Testimony of
Debbie Hatmaker, PhD, RN-BC, SANE-A**

**American Nurses Association
8515 Georgia Avenue, Suite 400
Silver Spring, MD 20910
301-628-5098 / 301-628-5348 (fax)**

**Before the
U.S. House of Representatives
Committee on Appropriations
Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies**

**Regarding
FY 2011 Appropriations for
Title VIII Nursing Workforce Development Programs**

May 12, 2010

10:00 A.M.

The American Nurses Association (ANA) appreciates this opportunity to comment on Fiscal Year (FY) 2011 appropriations for nursing education, workforce development, and research programs. Founded in 1896, ANA is the only full-service professional association representing the interests of the nation's 3.1 million registered nurses (RNs) through its constituent member nurses associations, its organizational affiliates, and its workforce advocacy affiliate, the Center for American Nurses. The ANA advances the nursing profession by fostering high standards of nursing practice, promoting the rights of nurses in the workplace, projecting a positive and realistic view of nursing, and by lobbying the Congress and regulatory agencies on health care issues affecting nurses and the public.

The ANA gratefully acknowledges this Subcommittee's history of support for nursing education and research. We also appreciate your continued recognition of the important role nurses play in the delivery of quality health care services. This testimony will provide an update on the status of the nursing shortage, its impact on the nation, and the outlook for the future.

The Nursing Shortage Today

The nursing shortage is far from solved. Here are a few quick facts:

- The Bureau of Labor Statistics reports that registered nursing will have remarkable job growth in the time period spanning 2006 – 2016. During this time decade, the health care system will require more than 1 million new nurses.
- The Health Resources and Services Administration (HRSA) projects that the supply of nurses in America will fall 26 percent (more than 1 million nurses) below requirements by the year 2020. In year 2020, Wisconsin's demand for full-time RNs will outstrip the supply by 20 percent (a shortage of 10,200 RNs). New York's shortage will reach 39 percent (54,200 RNs) and Ohio will have a 30 percent shortage (34,000 RNs). California's demand will outstrip its supply by 45 percent (116,600 RNs).

This growing nursing shortage is having a detrimental impact on the entire health care system. Numerous studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the January/February 2006 issue of *Health Affairs* showed that hospitals could avoid 6,700 deaths per year by increasing the amount of RN care provided to their patients. This study, "Nurse Staffing in Hospitals: Is There a Business Case for Quality?" by Jack Needleman, Peter Buerhaus, et al. also revealed that hospitals are currently providing four million days worth of inpatient care annually to treat avoidable patient complications associated with a shortage of RN care.

Research published in the October 23, 2002 *Journal of the American Medical Association* also demonstrated that more nurses at the bedside could save thousands of patient lives each year. In reviewing more than 232,000 surgical patients at 168 hospitals, researchers from the University of Pennsylvania concluded that a patient's overall risk of death rose roughly 7 percent for each additional patient above four added to a nurse's workload.

Nursing Workforce Development Programs

Federal support for the Nursing Workforce Development Programs contained in Title VIII of the Public Health Service Act is unduplicated and essential. The 107th Congress recognized the detrimental impact of the developing nursing shortage and passed the Nurse Reinvestment Act (PL 107-205). Most recently the 111th Congress reauthorized and improved upon these

programs. These updates improved the Title VIII Nursing Workforce Development programs to meet the unique characteristics of today's shortage. This achievement holds the promise of recruiting new nurses into the profession, promoting career advancement within nursing, and improving patient care delivery. However, this promise cannot be met without a significant investment. **ANA strongly urges Congress to increase funding for Title VIII programs by at least \$23 million (10% increase) to a total of \$267.3 million in FY 2011.**

Current funding levels are clearly failing to meet the need. In FY 2008 (most recent year statistics available), the Health Resources and Services Administration (HRSA) was forced to turn away 92.8% of the eligible applicants for the Nurse Education Loan Repayment Program (NELRP), and 53% of the eligible applicants for the Nursing Scholarship program due to a lack of adequate funding. These programs are used to direct RNs into areas with the greatest need – including departments of public health, community health centers, and disproportionate share hospitals.

In 1973, Congress appropriated \$160.61 million to Title VIII programs. Inflated to today's dollars, this appropriation would equal \$763.52 million, more than three times the FY 2010 appropriation. Certainly, today's shortage is more dire and systemic than that of the 1970's; it deserves an equivalent response.

Title VIII includes the following program areas:

Nursing Education Loan Repayment Program & Scholarships: This line item is comprised of the Nurse Education Loan Repayment Program (NELRP) and the Nursing Scholarship Program (NSP). In FY 2010, the Nurse Education Loan Repayment Program and Scholarships received \$93.8 million.

The NELRP repays up to 85 percent of a RN's student loans in return for full-time practice in a facility with a critical nursing shortage. The NELRP nurse is required to work for at least two years in a designated facility, during which time the NELRP repays 60 percent of the RN's student loan balance. If the nurse applies and is accepted for an optional third year, an additional 25 percent of the loan is repaid.

The NELRP boasts a proven track record of delivering nurses to facilities hardest hit by the nursing shortage. HRSA has given NELRP funding preference to RNs who work in departments of public health, disproportionate share hospitals, skilled nursing facilities, and federally-designated health centers. However, lack of funding has hindered the full implementation of this program. In FY 2008, 92.8 percent of applicants willing to immediately begin practicing in facilities hardest hit by the shortage were turned away from this program due to lack of funding.

The NSP offers funds to nursing students who, upon graduation, agree to work for at least two years in a health care facility with a critical shortage of nurses. Preference is given to students with the greatest financial need. Like the loan repayment program, the NSP has been stunted by a lack of funding. In FY 2008, HRSA received 3,039 applications for the nursing scholarship. Due to lack of funding, a mere 177 scholarships were awarded. Therefore, 2,862 nursing students (94 percent) willing to work in facilities with a critical shortage were denied access to this program.

Nurse Faculty Loan Program: This program establishes a loan repayment fund within schools of nursing to increase the number of qualified nurse faculty. Nurses may use these funds to pursue a master's or doctoral degree. They must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a four-year period. In FY 2010, this program received \$25 million.

This program is vital given the critical shortage of nursing faculty. America's schools of nursing cannot increase their capacity without an influx of new teaching staff. Last year, schools of nursing were forced to turn away tens of thousands of qualified applicants due largely to the lack of faculty. In FY 2008, HRSA funded 95 faculty loans.

Nurse Education, Practice, and Retention Grants: This section is comprised of many programs designed to support entry-level nursing education and to enhance nursing practice. The education grants are designed to expand enrollments in baccalaureate nursing programs; develop internship and residency programs to enhance mentoring and specialty training, and; provide new technologies in education including distance learning. All together, the Nurse Education, Practice, and Retention Grants supported 42,761 nurses and nursing students in FY 2008. The program received \$39.8 million in FY 2010.

Retention grant areas include career ladders and improved patient care delivery systems. The career ladders program supports education programs that assist individuals in obtaining the educational foundation required to enter the profession, and to promote career advancement within nursing. Enhancing patient care delivery system grants are designed to improve the nursing work environment. These grants help facilities to enhance collaboration and communication among nurses and other health care professionals, and to promote nurse involvement in the organizational and clinical decision-making processes of a health care facility. These best practices for nurse administration have been identified by the American Nurse Credentialing Center's Magnet Recognition Program[®]. These practices have been shown to double nurse retention rates, increase nurse satisfaction, and improve patient care.

Nursing Workforce Diversity: This program provides funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds - including racial and ethnic minorities, as well as individuals who are economically disadvantaged. In FY 2008, 85 applications were received for workforce diversity grants, 51 were funded. In FY 2010, these programs received \$16 million.

Advanced Nurse Education: Advanced practice registered nurses (APRNs) are nurses who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Most have practice experience as RNs prior to entering graduate school. Practice areas include, but are not limited to: anesthesiology, family medicine, gerontology, pediatrics, psychiatry, midwifery, neonatology, and women's & adult health. Title VIII grants have supported the development of virtually all initial state and regional outreach models using distance learning methodologies to provide advanced study opportunities for nurses in rural and remote areas. In FY 2008, 5,649 advanced education nurses were supported through these

programs. In FY 2010, these programs received \$64.4 million.

These grants also provide traineeships for master's and doctoral students. Title VIII funds more than 60 percent of U.S. nurse practitioner education programs and assists 83 percent of nurse midwifery programs. Over 45 percent of the nurse anesthesia graduates supported by this program go on to practice in medically underserved communities. A study published last year in the *Journal of Rural Health* showed that 80% of the nurse practitioners who attended a program supported by Title VIII chose to work in a medically underserved or health profession shortage area after graduation.

Comprehensive Geriatric Education Grants: This authority awards grants to train and educate nurses in providing health care to the elderly. Funds are used to train individuals who provide direct care for the elderly, to develop and disseminate geriatric nursing curriculum, to train faculty members in geriatrics, and to provide continuing education to nurses who provide geriatric care. In FY 2008, 6,514 nurses and nursing students were supported through these programs. In FY 2010, these grants received \$4.5 million. The growing number of elderly Americans and the impending health care needs of the baby boom generation make this program critically important.

CONCLUSION

While ANA appreciates the continued support of this Subcommittee, we are concerned that Title VIII funding levels have not been sufficient to address the growing nursing shortage. In preparation for the implementation of health care reform initiatives, which ANA supported, we believe there will be an even greater need for nurses and adequate funding for these programs is even more essential. ANA asks you to meet today's shortage with a relatively modest investment of \$267.3 million in Title VIII programs. Thank you.

May 6, 2010

CURRICULUM VITAE

Debbie D. Hatmaker, PhD, RN-BC, SANE-A
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 Atlanta, GA 30329-2655
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 404.325.0407 fax
 E-mail: dhatmaker@georgianurses.org

EDUCATION/CERTIFICATION

Medical College of Georgia, 1993, PhD, awarded "With Distinction"
 Medical College of Georgia, 1986, MSN, with highest honors
 University of Tennessee, Memphis, 1979, BSN
 Jefferson City High School, 1974, Diploma

Certification: Sexual Assault Nurse Examiner-Adult/Adolescent (SANE-A), 2002-present
 Nursing Professional Development (RN-BC), 2008-present

ADDITIONAL EDUCATION

Faculty Development Institute, University System of Georgia, Chancellor's Initiative for
 Connecting Teaching and Technology, 1998-1999
 Advanced: Forensic Evaluation of Sexual Assault Mini-Residency Program, University of
 Tennessee, Memphis, 59 contact hours, May 18-27, 1998
 Preparing Faculty for the Nursing Information Environment in Health Care: Crossing the Bridge
 to the 21st Century, SCCEN Workshop, June 9-13, 1997
 Sexual Assault Training Program: Focus on Pediatrics, 37 hours of didactic coursework, Scottish
 Rite Children's Medical Center, February 17-21, 1997.
 Credentialed a Sexual Assault Nurse Examiner, 40 hours didactic coursework April 22-26, 1996,
 54 clinical hours summer 1996; Athens-Clarke Co. Police Department and ACC-SANE

PROFESSIONAL**ACADEMIC APPOINTMENTS**

Coordinator, Educational Resources and Technology, Medical College of Georgia School of
 Nursing 2000-2002
 Coordinator, Educational Technology, Medical College of Georgia School of Nursing, 1999-
 2000
 Assistant Professor, Department of Parent-Child Nursing, Medical College of Georgia School of
 Nursing-Athens, Athens, GA, 1994-2002
 Instructor, Kaplan Educational Center, NCLEX testing, Atlanta GA, 1999
 Graduate Assistant, Department of Community Health Nursing, Medical College of Georgia

School of Nursing, Augusta, GA, 1993
 Instructor, Department of Parent-Child Nursing, Medical College of Georgia School of Nursing-
 Athens, Athens, GA, 1986-90
 Teaching/Research Assistant, Medical College of Georgia, Augusta, GA, 1985-86

CLINICAL PRACTICE

Sexual Assault Nurse Examiner, Athens-Clarke County SANE program, 1996-present
 RN Volunteer, Athens Nurses Clinic, 1992-2002
 Staff Nurse, Athens Regional Medical Center, Pediatrics Unit/PRN, Athens, GA, 1985-1986
 Staff Nurse, St. Mary's Hospital, Athens, GA, 1984-1985
 Staff Nurse, St. Vincent's Hospital, Jacksonville, FL, 1982-1984
 Public Health Nurse, Clay Co. Health Department, Green Cove Springs, FL, 1980-1982
 Public Health Nurse, Memphis-Shelby Co. Health Department, Memphis, TN, 1979-1980

GRANTS

Pfizer Medical Education Group, APRN Prescribing: Doing it Right and Avoiding Malpractice!,
 June 2006, award \$15,000
 Medical College of Georgia Teaching and Technology Grant, Informatics and Technology in
 Healthcare, July 2001, award \$7,700
 University System of Georgia Teaching & Learning Grant Program, Individual Professional
 Development, Faculty Development in the Area of Nursing Care for Sexual Assault
 Survivors, December 1997, award \$2,373
 Emmanuel Episcopal Church Williams-Rhodes Gifts, grant for administrative funds for Athens-
 Clarke County Sexual Assault Nurse Examiners Program, November 1997, award \$4,280

AWARDS/HONORS/CERTIFICATIONS

Certified Professional Nursing Development, RN-BC, 2008-present
 Georgia Nurses Association, District 11, Nurse of the Year, 2005
 Certified Sexual Assault Nurse Examiner Adult/Adolescent, SANE-A, 2002-present
 Georgia Nurses Association, Distinguished Service Award, 2002
 Who's Who Among America's Teachers, 1998, 2000
 Virginia H. Kemp Leadership award, Medical College of Georgia School of Nursing, May 1999
 Selected for the Faculty Development Institute, University System of Georgia, Chancellor's
 Initiative for Connecting Teaching and Technology, 1998-1999. Awarded \$7,500 for
 computer hardware/software and \$1,840 for travel allowance
 Spirit of Nursing Award, Selected by the faculty Medical College of Georgia School of Nursing,
 awarded by the Georgia Nurses Association, District 10, May 1998
 District Honoree, District 11 Georgia Nurses Association, 1997, 2002
 Awarded \$1,000 scholarship to attend SCCEN Workshop, June 9-13, 1997, "Preparing Faculty
 for the Nursing Information Environment in Health Care: Crossing the Bridge to the 21st
 Century"
 Outstanding Faculty Member, Medical College of Georgia School of Nursing, 1996-1997
 Drs. Vickie A. Lambert & Clinton E. Lambert Nursing Scholarship Award for Excellence in
 Scholarly Written Work, doctoral degree, June 1994

SCIENTIFIC AND PROFESSIONAL SOCIETIES

American Organization of Nurse Executives
 American Nurses Association, ANA convention delegate 1996, 1999-2002; Ex-officio Board member 2004-2006; First Vice President 2006-08, 2008-10
 American Nurses Credentialing Center, President 2007-2009, 2009-present
 Center for American Nurses, President, 2004-2006
 Georgia Nurses Association--State Level: President 1999-2002; President-Elect 1998-99; Chair, Advisory Board 1995-1996, 1996-1997
 Georgia Nurses Association--District Level: District 11 President, 1993-95, 1995-97; other offices: First Vice-President, Treasurer, Director; GNA convention delegate annually from 1986-1998
 International Association of Forensic Nurses
 International Association of Forensic Nurses, SANE Certification Examination Task Force, Member & Examination Item Writer, April 2001-2002
 International Association of Forensic Nurses, Forensic Nursing Certification Board, President, 2002-2004
 Journal of Child and Adolescent Psychiatric Nursing, Reviewer, 2001-2002
 Sigma Theta Tau, Beta Omicron Chapter, Director-SONAT, 1995-1997

COMMUNITY ACTIVITIES

State-wide Sexual Assault Nurse Examiner Educator 1999-present
 Georgia Hospital Association, Workforce Council member, 2001-present
 Sexual Assault Nurse Examiner with the Athens-Clarke County SANE program, April 1996-present
 Georgia Network to End Sexual Assault (GNESA) SANE Education Committee, 1999-2006
 Health Care Workforce Policy Advisory Committee, Governor's appointed member representing Registered Nursing, 2001-2004
 Georgia Sexual Assault Task Force of the Women's Health Section, Family Health Branch, Georgia Division of Public Health, 1997-1998
 Oconee County United Way Advisory Board, 1997
 Advisory Board of Northeast Georgia Rape Crisis Center, September 1995-1996
 Advisory Board of Athens Sexual Assault Nurse Examiner Program, September 1995-1996
 Member of Athens 96 Medical Resources Team for 1996 Olympics, June 1995-July 1996

PRESENTATIONS AND WORKSHOPSConference & Classroom Presentations

Multiple presentations as GNA President & Chief Programs Officer—1999-present
 "Why Certification Matters", Invited Speaker, Delaware Nurses Association Spring Conference, March 12, 2010
 "Credentialing as a Commitment to Excellence", Invited Speaker, Sheikh Khalifa Medical City, Abu Dhabi, May 14, 2009

- “Credentialing as a Commitment to Excellence”, Invited Speaker, International Nurses Day Conference, Dubai, UAE, May 16, 2008.
- “ANA & You: Hot Issues in Nursing”, Invited Speaker, Arizona Nurses Association, Scottsdale, AZ, September 21, 2007.
- “Professional Growth and Transitions: The DNP”, Invited Panelist, Arizona Nurses Association, Scottsdale, AZ, September 21, 2007.
- “Hallmarks – A Leader for Workforce Advocacy”, Invited Speaker, North Carolina Nurses Association Convention, Winston-Salem, North Carolina, October 11, 2006.
- “Transforming Nursing Work Environments to Enhance Patient Safety and Quality”, Invited Speaker, Arizona Nurses Association Convention, Tucson, Arizona, September 23, 2005.
- “Transforming Nursing Work Environments to Enhance Patient Safety and Quality: What CMAs and Nursing Leaders Can Do”, Invited Speaker, Wisconsin Nurses Association Convention, Delavan, Wisconsin, October 29, 2004.
- “The Georgia Nurse Alert System: Mobilizing Nurses During Times of Disaster”, International Association of Forensic Nursing Scientific Assembly, Las Vegas, Nevada, September 27, 2003.
- “Environmental Workforce Issues”, Invited Panel Speaker, Georgia Organization of Nurse Leaders, Savannah, Georgia, September 3, 2003.
- “This Patient Needs a (Forensic) Nurse”, Panel Speaker, International Association of Forensic Nursing Scientific Assembly, Orlando, Florida, September 29, 2001.
- “Nurturing the Nurse”, Invited luncheon speaker, East Georgia Chapter, Association of Women's Health, Obstetric, and Neonatal Nurses, Augusta, GA, January 26, 2001.
- “Workplace Advocacy”, Invited speaker, Georgia Organization of Nurse Executives Annual Meeting, Savannah, GA, September 15, 2000.
- “Instructional Technology”, Invited Panel guest for the Governor's Teaching Fellows and the Instructional Technology Leadership Program, University System of Georgia, Athens, GA, May 15, 2000.
- “Evaluating Sexual Assault”, Clinical Update for Nurse Practitioners and Physician Assistants, Athens, GA, November 7, 1999.
- “Forensic Nursing Online”, Georgia Association of Nursing Students Annual Convention, Macon, GA, October 1, 1999.
- “Georgia Nurses Association: Current Challenges and Future Directions”, Georgia Association of Nursing Students Annual Convention, Macon, GA, October 1, 1999.
- “A Community Based Approach to Sexual Assault”, International Association of Forensic Nursing Scientific Assembly, Pittsburgh, Pennsylvania, October 3&4, 1998.
- “The Development of a State-wide SANE Education Program in Georgia: Bumpy Roads and Detours”, International Association of Forensic Nursing Scientific Assembly, Pittsburgh, Pennsylvania, October 3&4, 1998.
- “Maternal Mood, Facial Affect Recognition and Maternal-Infant Interaction”, National Conference of the Association of Child & Adolescent Psychiatric Nurses, September 19, 1998.
- “Role of the Nurse in Pediatric Sexual Assault”, Caring for Children Regional Conference, Augusta, GA, May 12, 1997.
- “A SANE Approach to Sexual Assault”, Women's Health Studies, Graduate Course in Department of Health Promotion, University of Georgia, Athens, GA, February 11, 1997.

- “A SANE Approach to Sexual Assault”, Georgia Association of Nursing Students Annual Convention, Savannah, GA, February 7, 1997.
- “Women’s Health Breakout Session”, The UN Women’s Conference: One Year Later, University of Georgia, Women’s Studies Program, Athens, GA, September 28, 1996.
- “Perception of threat and subjective well-being in low-risk and high-risk pregnant women”, Southern Nursing Research Society Ninth Annual Conference, Lexington, KY, February 17, 1995.
- “Health practices and subjective well-being in low-and high-risk pregnant women”, International Nursing Research Conference, Vancouver, B.C., Canada, May 5, 1994.

Invited Workshops

- “Sexual Assault Nurse Examiners Program”, SANE Education Program, 3-4 times/year, 2 ½ day seminars at various locations around the state of Georgia, 1999-present.
- “Sexual Assault Nurse Examiners Program”, Pee Dee Coalition, Florence, South Carolina, June 3-4, 2000.
- “Sexual Assault Nurse Examiners Program”, Medical College of Georgia School of Nursing, May 15-19, 2000.
- “Sexual Assault Nurse Examiners Program”, Rutgers University College of Nursing, Newark, New Jersey, March 16, 2000.

PROFESSIONAL EXHIBITS

- “Health practices and subjective well-being in low-and high-risk pregnant women”, Poster presentation, Georgia Nurses Association Annual Convention, Columbus, GA, October 19, 1995.
- “Health practices and subjective well-being in low-and high-risk pregnant women”, Poster presentation, Perinatal Home Care Conference, Baltimore, MD, December 5, 1994

PUBLICATIONS

Books/Chapters

- Hatmaker, D.D. Workforce Advocacy and the Nursing Shortage, In B. Cherry & S. Jacobs (Eds.) Contemporary Nursing: Issues, Trends and Management, 5th Ed. In press.
- Green, A., Hatmaker, D.D., Tabone, S. Workforce Advocacy and the Nursing Shortage, In B. Cherry & S. Jacobs (Eds.) Contemporary Nursing: Issues, Trends and Management, 4th Ed. St Louis: Elsevier, 2008.

Journals

- Hatmaker, D.D., Pinholster, L., & Saye, J. A Community-Based Approach to Sexual Assault. Public Health Nursing 19(2), 124-127, 2002.
- Hatmaker, D.D., Nurses: Keeping the Care in Health Care. Advance for Nurses, 2 (9), 6, 2000.
- Hatmaker, D. D., & Kemp, V. H. Perception of threat and subjective well-being in low-risk and high-risk pregnant women. Journal of Perinatal and Neonatal Nursing, 12 (2), 1-10, 1998.

- Hatmaker, D. D. A SANE approach to sexual assault. American Journal of Nursing, 97 (8), 80, 1997.
- Kemp, V. H. & Hatmaker, D. D. Perinatal home care. Family & Community Health, 18, 40-48, 1996.
- Kemp, V. H. & Hatmaker, D. D. Health practices and anxiety in low-income, high- and low-risk pregnant women. Journal of Obstetric, Gynecologic, and Neonatal Nursing, 22, 266-272, 1993.
- Kemp, V. H. & Hatmaker, D. D. Stress and social support in high-risk pregnancy. Research in Nursing & Health, 12, 331-336, 1989.

Editorials, Abstracts, and Columns

- Hatmaker, D.D. The More Things Change, Georgia Nursing, 62 (2), 2002.
- Hatmaker, D.D. It's All About the Workplace. Georgia Nursing, 62 (1), 2002.
- Hatmaker, D.D Focused on the Future. Georgia Nursing, 61 (4), 2001.
- Hatmaker, D.D. Preaching to the Choir. Georgia Nursing, 61 (3), 2001.
- Hatmaker, D.D. Rock the boat. Georgia Nursing, 61 (1), 2001.
- Hatmaker, D.D. Responding to the challenge. Georgia Nursing, 60 (4), 2000.
- Hatmaker, D.D. It's a great time to be a nurse. Georgia Nursing, 60 (3), 2000.
- Hatmaker, D.D. Finding ways to keep the care in healthcare. Atlanta Journal Constitution, May 7, 2000, R31.
- Hatmaker, D.D. The reality of nursing practice in the 21st century. Georgia Nursing, 60 (2), 2000.
- Hatmaker, D.D. Make a difference. Georgia Nursing, 60 (1), 2000.
- Hatmaker, D.D. Transformation. Georgia Nursing, 59 (4), 1999.
- Hatmaker, D.D. Provision of services for sexual assault survivors: An update. Georgia Nursing, 58 (3), 1998.
- Hatmaker, D., Pinholster, L., Saye, J., A community based approach to sexual assault. (Abstract) Abstracts of the 1998 International Conference of the International Association of Forensic Nurses. 357, 1998
- Allen, E., Froncek, P., Hatmaker, D., Lawson, L., Speck, P., Various models of state-wide SANE education. (Abstract) Abstracts of the 1998 International Conference of the International Association of Forensic Nurses. 177, 1998
- Bennett, G., Hatmaker, D., Saunders, J., Woodring, B., Desmond, A.M., Walker, J., Killeen, M., Maternal mood, facial affect recognition and maternal-infant interaction. (Abstract) Abstracts of the 1998 National Conference of the Association of Child and Adolescent Psychiatric Nursing. 27:46-46, 1998.

Mr. OBEY. Thank you.
Next, Cheryl Phillips, American Geriatrics Society.

WEDNESDAY, MAY 12, 2010.

AMERICAN GERIATRICS SOCIETY

WITNESS

CHERYL PHILLIPS, MD, AGSF, PRESIDENT, AMERICAN GERIATRICS SOCIETY

Dr. PHILLIPS. Again, thank you, Chairman Obey and members of this special Subcommittee. This is a remarkable opportunity and I wish to take advantage to talk about funding for fiscal year 2011 to improve care for America's older adults.

My name is Cheryl Phillips, and I am a fellowship-trained geriatrician, a rare breed these days and becoming rarer. I am also President of the American Geriatrics Society, the Nation's largest professional organization which represents the interdisciplinary health care professionals serving America's older adults, particularly those with complex chronic needs, medical conditions, frailty, and the risk for functional decline.

The 2008 Institute on Medicine Report that I know you are all familiar with, *Retooling for an Aging America*, noted the severe shortage of geriatric health professionals and called for initiatives to increase recruitment into geriatrics and ensure all health care professionals are adequately trained to serve America's older adults.

If we are going to fulfill our promises of health care reform that have been articulated in the Act, we need sufficient and sustained Federal investment to educate and train geriatric health professionals across all disciplines, which includes physicians, nurses, social workers, mental health professionals, pharmacists, therapists, all of which make up this geriatric team—it is indeed a team sport—which has demonstrated both the improvement in quality and cost-reduction and cost-effectiveness for this very vulnerable and fragile group of individuals that we serve.

The Patient Protection and Affordable Care Act authorizes geriatric health professions programs under Titles VII and VIII, as we have been talking about with the previous speakers. Specifically, AGS requests funding for the fiscal year 2011 in the following areas: \$49.7 million for Title VII Geriatrics Health Professions Programs.

There are three key Federal initiatives under this Title VII appropriations area. One is called the Geriatric Academic and Career Awards, also known as GACAs; second are the Geriatric Education Centers, one of which is in Marquette University in Milwaukee that has served over 50,000 individuals in the 15 years of its operation in reducing thousands and thousands of dollars of medical costs for the population served; and then also the Geriatric Health Faculty Fellowships.

All of these are required and essential to create the next generation of health care professionals in order to serve the increasing numbers of seniors. These programs have been underfunded and,

in fact, as has been mentioned earlier, there was no funding in 2006.

We are also asking for a relatively small \$3.34 million—although in these days every penny counts, I know. But this is specific funding for direct care workforce training. This is the silent army of workers that is often unrecognized in training programs. These are those individuals who do the direct care, the bedside care, often unlicensed, but need training for recruitment, for skills enhancement, and for sustenance to maintain this growing body of need for our elder Americans.

We are asking for \$15.7 million for Title VIII, as was just previously mentioned, specifically for the geriatric nursing workforce. We recognize that the nursing personnel must receive adequate education and training to serve all of our frail Americans; and specifically 200 traineeships for advanced practice nurses.

Lastly, briefly mentioning the National Institute on Aging. It is the NIA funding that is essential to make advances today that lead to higher quality and cost-efficient care for tomorrow. We request that funding be restored to 2003 fiscal year funding levels, taking in account medical inflation.

In closing, geriatrics is at a critical juncture. Our Nation is facing an unprecedented increase in the number of older patients with complex health needs. We acknowledge the work that you have done. We appreciate your past commitment, your continued commitment, and on behalf of the American Geriatrics Society, we thank you for your continued support for the health and quality of life for older Americans.

Thank you very much.

[Written statement by Cheryl Phillips follows:]

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STATEMENT OF

CHERYL PHILLIPS, MD, AGSF

CHIEF MEDICAL OFFICER,
ON LOK LIFEWAYS, SAN FRANCISCO, CA

&

PRESIDENT,
AMERICAN GERIATRICS SOCIETY

ON BEHALF OF THE

AMERICAN GERIATRICS SOCIETY



BEFORE THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

HOUSE APPROPRIATIONS COMMITTEE
UNITED STATES HOUSE OF REPRESENTATIVES

ON TITLE VII GERIATRICS HEALTH PROFESSIONS PROGRAMS,
TITLE VIII COMPREHENSIVE GERIATRIC EDUCATION NURSING PROGRAM
& THE NATIONAL INSTITUTE ON AGING

MAY 12, 2010
10:00 AM – 12:30 PM

INTRODUCTION

Good afternoon Chairman Obey, Ranking Member Tiahrt, and Members of the Subcommittee:

I would like to express my sincere appreciation to Chairman Obey and the members of the Subcommittee for the opportunity to provide testimony today on the critical need to adequately fund programs that improve the care delivered to older Americans.

My name is Cheryl Phillips, M.D. I am a fellowship-trained geriatrician and chief medical officer of On Lok Senior Services, the originator of the PACE (Program of All-Inclusive Care for the Elderly). I also serve as President of the American Geriatrics Society, a non-profit organization of 6,400 geriatrics healthcare professionals dedicated to improving the health, independence and quality of life of all older Americans.

Today, I will briefly outline the need to provide the highest possible funding levels in the FY 2011 Labor, Health and Human Services, and Education appropriations bill for geriatrics education and training programs under Title VII and Title VIII of the Public Health Service Act. AGS is grateful to the Subcommittee for its long-standing support of these programs, as demonstrated by the increased funding levels recommended in FY 2010. In addition, I will discuss the importance of increased support in FY 2011 for the National Institute on Aging. Increased federal investments in a well-trained and educated geriatrics healthcare workforce and a strong biomedical aging research program are both essential to fulfilling the promise of health reform to deliver higher quality and better coordinated care to our nation's seniors. As America's 77 million baby boomers age, the need to increase the number of geriatrics health professionals and to enhance our capacity to train the nation's healthcare workforce on the unique healthcare needs of older adults is great. Older Americans use more health care services and their conditions are often complex. Often, the team of geriatrics professionals – physicians, nurses, pharmacists, mental health providers and social workers, among others – is best equipped to deliver the comprehensive, coordinated, high-quality and cost-effective care to these older patients with complex health needs.

The findings of the Institute of Medicine's (IOM) ground-breaking 2008 report, *Retooling for an Aging America: Building the Healthcare Workforce*, underscore the importance of geriatrics training and education programs across disciplines. Noting the severe shortage of geriatrics healthcare professionals, the report calls for a wide range of broad initiatives to increase recruitment into geriatrics and ensure that all healthcare providers who care for older adults are adequately trained. There are 7,590 geriatricians in the U.S. – one geriatrician for every 2,500 Americans 75 or older. Due to the projected

increase in the number of older Americans, this ratio is expected to drop to one geriatrician for every 4,254 older Americans in 2030.

The Patient Protection and Affordable Care Act (PPACA) includes critical healthcare workforce enhancements to the Title VII and VIII geriatrics training and education programs based on the IOM's recommendations and drawn from legislation sponsored by Senator Kohl and Representative Schakowsky, the *Retooling the Health Care Workforce for an Aging America Act*. These provisions (PPACA Sec. 5305) expand existing and create new programs that will increase the capacity of our nation's geriatrics healthcare workforce. Our request includes funding to implement these timely and important new and expanded geriatrics healthcare workforce programs and also assumes a 10% increase on existing Title VII and VIII geriatrics programs.

We ask that the subcommittee consider the following recommended funding levels for these programs under the Public Health Service Act:

- \$49.7 million for Title VII Geriatrics Health Professions Programs
- \$3.34 million for Title VII Direct-Care Workforce Training Program
- \$15.7 million for Title VIII Comprehensive Geriatric Education Nursing Program

Title VII Geriatrics Health Professions Programs

Funding for Title VII Geriatrics Health Professions Programs is a proven investment in ensuring that older adults receive high quality healthcare now and in the future. These programs support three initiatives: the Geriatric Academic Career Awards (GACAs), the Geriatric Education Center (GEC) program, and geriatric faculty fellowships, the only programs specifically designed to address the evident shortage of geriatrics healthcare professionals in the U.S. Strong and sustained investments are important to reversing the chronic under-funding of these essential programs at a time when our nation is facing a critical shortage of geriatrics healthcare professionals across disciplines. **We ask the subcommittee to provide a FY 2011 appropriation of \$49.7 million for Title VII Geriatrics Health Professions Programs.**

Our funding request of \$49.7 million breaks down as follows:

- Geriatric Academic Career Awards (GACAs) (\$20 million)
GACAs support the development of newly trained geriatric physicians in academic medicine who are committed to teaching geriatrics in medical schools across the country. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of healthcare professionals. In FY 2009, there were 84 GACAs funded with a budget of approximately \$6.4 million. Under the new health reform law, the GACA program expands eligibility to a variety

of new disciplines beyond physicians, including those in nursing, social work, psychology, dentistry, and pharmacy. AGS has long advocated for this change. We must now ensure that there is adequate funding to meet the increased demand given the greater number of disciplines eligible for the award. A budget of \$20.0 million would support 250 awardees at \$80,000 per award.

- Geriatric Education Centers (GECs) (\$20.57 million)

GECs provide grants to support collaborative arrangements involving several health professions, schools and healthcare facilities to provide multidisciplinary training in geriatrics, including assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans. Over 90 percent of GECs are a consortia of three or more colleges, hospitals, community agencies and Area Health Education Centers that reach many health providers. For example, the Wisconsin Geriatric Education Center (WGEC) is a formal consortium of academic and health care organizations dedicated to creating educational resources and training opportunities in geriatrics for health professionals, faculty, practitioners, and students in Wisconsin. Over 50,000 people have participated in WGEC-sponsored programs between 1986 and 2001, including professionals from more than 35 different disciplines and practicing throughout Wisconsin's rural and urban communities. Overall, in 2005 alone, the National Association of Geriatric Education Centers reports that Title VII-funded Geriatric Education Centers delivered low-cost geriatrics training interventions to more than 50,000 healthcare providers who collectively reported over 8.6 million appointments with older patients.

In FY 2009, there were 48 GECs funded nationwide with a budget of approximately \$16 million. Under PPACA, Congress authorized \$10.8 million over three years for a supplemental grant award program that will train additional faculty through an intensive short-term fellowship program and also requires faculty to provide training to family caregivers and direct-care workers. Our funding request includes continued support for the core work of 48 GECs and for up to 24 GECs to be funded to undertake the work through the supplemental grant program.

- Geriatric Training Program for Physicians, Dentists, and Behavioral and Mental Health Professions (\$5.8 million)

This program is designed to train physicians, dentists, and behavioral and mental health professionals who choose to teach geriatric medicine, dentistry or psychiatry. The program provides fellows with exposure to older adult patients in various levels of wellness and functioning, and from a range of socioeconomic and racial/ethnic

backgrounds. In FY 2009, there were 10 training programs funded with a budget of approximately \$5.2 million.

- Geriatric Career Incentive Awards Program (\$3.33 million)

This is a new award created under health reform. Under health reform, Congress has authorized grants to foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management.

Title VII Direct-Care Workforce Training Program

We also need to invest in efforts to improve training and enhance the recruitment and retention of direct-care workers, particularly those in long-term care settings. As our population ages, these workers will be an integral part of efforts to ensure that older adults have access to high quality care. Under PPACA, Congress established a program that will offer advanced training opportunities for direct-care workers. **AGS requests that the subcommittee provide \$3.34 million in FY 2011 for the Title VII Direct-Care Workforce Training Program established under PPACA.**

Title VIII Comprehensive Geriatric Education Nursing Program

The American health care delivery system for older adults will be further strengthened by federal investments in Title VIII Nursing Workforce Development Programs, specifically the comprehensive geriatric education grants, as nurses provide cost-effective, quality care. Increasing funding for the nursing comprehensive geriatric education program would be highly cost-effective. This program supports additional training for nurses who care for the elderly, development and dissemination of curricula relating to geriatric care, and training of faculty in geriatrics. It also provides continuing education for nurses practicing in geriatrics. **AGS requests that the subcommittee provide \$15.7 million for the Title VIII Comprehensive Geriatric Education Nursing Program in FY 2011.**

Under the new health reform law, this program is being expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing or other nursing areas that specialize in the care of older adults. Our funding request includes funds to offer 200 traineeships to nurses under this newly expanded program.

National Institute on Aging

AGS respectfully requests your strong support for increased funding in FY 2011 for the National Institutes of Health and specifically for the National Institute on Aging (NIA). Robust medical research in aging is central to making medical advances that ultimately lead to higher quality and more efficient health care, two important goals of health reform under PPACA. Continued and strong federal investments in scientific research

will ensure that the NIA has the resources to succeed in its mission to establish research networks, assess clinical interventions and disseminate credible research findings to patients, providers and payers of health care.

According to the Congressional Research Service, in FY 2003, NIH reached the peak of its purchasing power from regular appropriations when Congress completed a five-year doubling of the NIH budget. In each year since then, NIH's buying power has declined because its annual appropriations have grown at a lower rate than the inflation rate for medical research. Taking inflation into account, the FY 2010 funding level is about a 12.6% decrease in purchasing power from FY 2003.

Flat funding of NIH since 2003 has also led to declining numbers of young investigators choosing research careers, given the scarcity of funding to support their career development. We must provide the resources and tools to support the next generation of investigators and expand the pool of clinical researchers focused on advancing aging research.

AGS is concerned that the essential work of the NIH and NIA will be constrained unless funding can be increased and sustained. **Our recommendation and request is for funding to be increased to levels that restore NIA and NIH budgets to their historical FY 2003 levels (taking medical inflation into account).** The NIH and the NIA in particular need this level of funding to put the best science to work for the benefit of our nation's aging population as well as for all Americans.

In closing, geriatrics is at a critical juncture, with our nation facing an unprecedented increase in the number of older patients with complex health needs. Strong support such as yours will help ensure that the promise of health reform is fulfilled and every older American is able to receive high-quality health care.

On behalf of all the members of the American Geriatrics Society, we commend you on your past and continued support for programs to improve the health and quality of life for older Americans.

Thank you for your consideration.

Cheryl Phillips, MD, AGSF

Cheryl Phillips, MD, Chief Medical Officer for On Lok Lifeways -- the San Francisco-based originator of the Program of All-inclusive Care for the Elderly (PACE) model that serves nursing home eligible seniors -- was named President of the American Geriatrics Society (AGS) in May 2009.

An AGS member for 20 years, Dr. Phillips previously served as Secretary of the Society and has been an AGS Board member since 2003. She was both a member and Vice-Chair of AGS' Health Systems Committee. And in 2002, she served as AGS' representative to the Primary Health Care Policy Fellowship under Department of Health and Human Services Secretary Tommy Thompson. Dr. Phillips has testified before the U.S. Senate Special Committee on Aging regarding integrating care for persons with Alzheimer's disease. In 2005 California Gov. Arnold Schwarzenegger appointed her a governor's delegate to the White House Conference on Aging. She has also been appointed to the California Commission on Aging and the California Olmstead Committee.

Prior to joining On Lok, Dr. Phillips was the Chief Medical Officer for Sutter Select and the director of Chronic Care and Disease Management for Sutter Health, an integrated health care system in Northern California. While working at Sutter Health, Dr. Phillips developed a risk screening and care coordination program for high risk elders and those with advanced chronic diseases that, at the time she left, served 8,000 patients annually in the greater Sacramento area. She was also the geriatric education coordinator for the Sutter Family Practice residency program, for which she developed a functional assessment teaching clinic, a nursing home continuity residency practice, and a geriatric didactic curriculum.

Dr. Phillips completed her family practice residency and geriatric fellowship at the University of California, Davis, where she held a faculty appointment as Clinical Professor in the Department of Family Practice until 2008, when she accepted the position at On Lok Lifeways.

Dr. Phillips is also a past-president of the American Medical Directors Association (AMDA). She has served on multiple national boards and advisory groups for chronic care including: the National Chronic Care Consortium Executive Committee, the Centers for Medicare and Medicaid Services Technical Expert Panel on Quality Indicators in Long-Term Care, the Geriatric Measurement Advisory Panel for the National Committee for Quality Assurance, and the Atlantic Philanthropies' Practice Change Fellowship for Leaders in Geriatric Care.

Mr. OBEY. Thank you.
Next, Peggy Troy, National Association of Children's Hospitals.

WEDNESDAY, MAY 12, 2010.

NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

WITNESS

PEGGY TROY, RN, MSN, PRESIDENT AND CEO, CHILDREN'S HOSPITAL AND HEALTH SYSTEM, WISCONSIN, NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

Ms. TROY. Chairman Obey and members of the Subcommittee, thank you for the opportunity to testify today in support of Children's Hospitals Graduate Medical Education, CHGME. I am Peggy Troy, President and Chief Executive Officer of Children's Hospital and Health System of Wisconsin. I am here today on behalf of the National Association of Children's Hospitals and the 60 independent children's teaching hospitals that qualify for CHGME funding.

Congress established the CHGME program in 1999 to address a disparity in Federal graduate medical education support that existed between adult teaching hospitals and independent children's hospitals. Because our hospitals treat kids, and not the elderly, they are largely excluded from the predominant payer of graduate medical education, Medicare.

Prior to CHGME, children's teaching hospitals received less than .5 percent of the Federal GME support that adult teaching hospitals received. Thanks to the Subcommittee's leadership and the broad bipartisan congressional support, the CHGME program currently provides about 80 percent of the GME that Medicare provides to trained adult physicians.

CHGME funding is critical to the future of pediatric medicine and access to care. This funding has allowed children's hospitals to address a large gap that exists between a child's need for pediatric subspecialty care and the supply of pediatricians who are trained for their unique needs.

CHGME has shown remarkable success in erasing the decline of the number of pediatric residencies that existed prior to its enactment. It has enabled children's hospitals to sustain and expand our residency programs at a time of national specialist workforce shortages in pediatrics. In fact, freestanding children's hospitals that receive this funding have accounted for 65 percent of the growth in pediatric specialty programs.

To give you an idea of the impact, since 1999, prior to the enactment of the CHGME, Children's Hospital of Wisconsin had 65 pediatric residents rotating through our program. This past year we trained 113 pediatric medical and dental residents.

You may be interested to know that the leading cause of absenteeism for children from schools today is dental pain. So it is important we also consider the dentists in this.

Because we now have dedicated CHGME funding for our training programs, we can target other resources to better serve all children in our regions. These funds provide vital primary care training for our pediatric residents at the Downtown Health Center in Mil-

waukee. The Center serves as a medical home for 5400 low-income vulnerable children every year. Because of this experience, half of our graduating residents go into primary care and about a quarter of them serve in urban and rural underserved areas.

CHGME funding is critical. It ensures that the safety net children's hospitals, like us, can continue to care for all children, irrespective of their parents' ability to pay. Nearly 50 percent of all of our services at Children's in Milwaukee is supported by Medicaid. Similar figures exist for the freestanding children's hospitals across our Nation.

In 2006, Congress reauthorized the CHGME program with overwhelming bipartisan support, providing \$330 million in authorized funding. Last year, the House approved an appropriation of \$320 million for the program, \$10 million above the 2009 funding level.

The final funding level for CHGME in 2010 was \$317.5 million, and President Obama maintained this funding level in his fiscal year 2011 budget request. We deeply appreciate the support of this program and what it has received by the members of this Subcommittee, and, Chairman Obey, we personally really appreciate all the support that you have given for the health care and education needs of the citizens across the Country.

We are grateful for the leadership of you and Ranking Member Tiahrt for supporting this program.

CHGME is a targeted, fiscally responsible, slow growth program that operates under extensive data reporting requirements. CHGME is important to the Nation's children's hospitals and is absolutely critical to children's health and the future of pediatric medicine. Our training program represents less than 1 percent of all hospitals, but trains 35 percent of all pediatricians, 50 percent of all pediatric specialists, and a great majority of the researchers.

As our workforce prepares for the increased volume as a result of health care reform, this is going to play a very, very important role. We thank you and the members of this Committee for your support.

You have heard today from many of the children's programs, the safety net programs. Health and education are inextricably linked. We appreciate your support for this and we would hope that you would guarantee the success of the future of the CHGME program by appropriating the fully authorized level of \$330 million in fiscal year 2011.

Thank you very much for your support.

[Written statement by Peggy Troy follows:]

National Association of
Children's Hospitals
Champions for Children's Health



N · A · C · H

Testimony of Ms. Peggy Troy RN, MSN
President and Chief Executive Officer, Children's Hospital & Health System
Milwaukee, WI

May 12, 2010 - 10:00 a.m.

on behalf of

The National Association of Children's Hospitals
Alexandria, Virginia

Summary of Testimony in Support of Full Funding for the Children's Hospitals Graduate Medical Education Program respectfully submitted to the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies of the House Committee on Appropriations

Ms. Peggy Troy will testify about the importance of the Children's Hospitals Graduate Medical Education (CHGME) program. CHGME is administered by the Bureau of Health Professions in the Health Resources and Services Administration at the Department of Health and Human Services.

Ms. Troy's testimony focuses on the purpose of CHGME and its benefit to all children. Further, the testimony describes how CHGME has allowed Children's Hospital Wisconsin to fulfill its academic and clinical care missions.

The testimony concludes by respectfully asking the subcommittee to appropriate full authorized funding -- \$330 million -- for CHGME in Fiscal Year 2011.

On behalf of the National Association of Children's Hospitals (N.A.C.H.) and the nation's free-standing children's hospitals, I respectfully request that the Labor-HHS Appropriations Subcommittee provide the fully authorized funding level of \$330 million for the Children's Hospitals Graduate Medical Education (CHGME) program in FY 2011.

With the subcommittee's leadership, Congress has worked to provide equitable funding for the nation's independent children's teaching hospitals through the CHGME program. An appropriation of \$330 million would meet the program's authorization level and ensure that children's hospitals will receive equitable funding compared to the federal support that other teaching hospitals receive through Medicare.

In 2006, Congress reauthorized the CHGME program with overwhelming bipartisan support. Since then the Labor-HHS Subcommittee has provided strong, consistent funding for CHGME under the tireless leadership of Chairman Obey and Ranking Member Tiahrt. In FY 2010, the House approved an appropriation of \$320 million for the program – \$10 million above the FY 2009 funding level. The Senate Appropriations Committee provided \$315 million for CHGME in FY 2010. The final funding level for CHGME in FY 2010 was \$317.5 million, which is the highest amount the program has ever received. In his FY 2011 budget request, President Obama also recognized the importance of CHGME and maintained funding at \$317.5 – \$7.5 million above his request for FY 2010.

CHGME is a targeted, fiscally responsible, slow-growth program that is integral to ensuring a stable future for children's hospitals and the pediatric workforce. Congress created CHGME in 1999 because it recognized the importance of a well-trained pediatric workforce and understood the disparity in federal graduate medical education (GME) support that existed between adult teaching hospitals and independent children's teaching hospitals. At that time, independent children's teaching hospitals were effectively left out of federal GME support provided through Medicare because they treat children and not the elderly. In fact, children's hospitals were at a serious financial disadvantage, receiving less than 0.5 percent of the federal GME support of other teaching hospitals. Medicaid GME payments, which are left to the discretion of states to provide and are well below the costs related to training, did not fill the gap.

Congress also understood when it created CHGME that the disparity in GME support under Medicare jeopardized an already precarious pipeline of pediatric specialists. As a result of congressional foresight and commitment to this program, CHGME has played a critical role in addressing the nation's serious shortage of pediatric specialists.

Independent children's teaching hospitals, such as Children's Hospital of Wisconsin, represent less than 1 percent of all hospitals and train 35 of all general pediatric residents, half of all pediatric specialty fellows, the great majority of pediatric researchers, and many other physicians who require pediatric training. In addition, they provide half of all hospital care to seriously ill children and serve as the nation's premier pediatric research centers.

CHGME funding now provides children's hospitals with about 80 percent of the GME support that Medicare provides to adult teaching hospitals. The funding has enabled children's hospitals to expand pediatric training programs, improve the quality and depth of their training, and prevent a net decline in the number of pediatric residents.

Since the program's inception, children's hospitals have more than doubled the number of total pediatric specialty residents in response to local, regional and national needs and children's hospitals have increased the number of new training programs by approximately 50 percent. Because Children's Hospital of Wisconsin now has dedicated CHGME funding for our training programs, we can target other resources to better serve all children in our region. These funds provide vital primary care training for Children's Hospital of Wisconsin's pediatric residents at the Downtown Health Center located in the heart of Congresswoman Gwen Moore's district, which serves as a medical home for 5,400 low-income, vulnerable children in Milwaukee. More than 35 residents provide weekly primary and preventive care services to these children, and 82 residents have month-long training in acute care. Half of graduating residents enter primary care, and nearly one-quarter work in underserved areas.

Unfortunately, shortages in the pediatric workforce still remain, particularly in pediatric specialty care. The National Association of Children's Hospitals and Related Institutions' (NACHRI) 2009 Pediatric Subspecialty Survey found a strong connection between pediatric specialty shortages, long-term vacancies and children's access to timely and appropriate health care. According to the survey, national shortages contribute to vacancies in children's hospitals that commonly last 12 months or longer for a number of pediatric specialties, including pediatric neurology, developmental-behavioral pediatrics, pediatric endocrinology, pediatric pulmonology, and pediatric gastroenterology.

Sick children bear the brunt of the shortages of pediatric specialists. Wait times for scheduling appointments with pediatric specialists often exceeds the prevailing national benchmark of two weeks. In fact, at least half of children's hospital survey respondents reported wait times far longer than two weeks. For example:

- 68 percent of children's hospitals experience difficulty scheduling endocrinology visits; the average wait time is over 10 weeks
- 61 percent report difficulty scheduling neurology visits; the average wait time is 9 weeks
- 50 percent report difficulty scheduling developmental pediatrics visits; the average wait time is over 13 weeks. This exceptionally long wait time is of particular concern given the rise in autism-related disorders among the nation's children.

A January 2010 Wall Street Journal article, "*For Severely Ill Children, a Dearth of Doctors*," put a human face on the NACHRI survey findings and described the impact of these shortages on a young patient and his family. "Three-year old Kenneth Jones, for example, was born in Alaska with a rare gastrointestinal disorder that made him unable to absorb protein. He had to travel three hours to see one pediatric GI specialist in the

state—a doctor who left a year later. The family moved to Oregon for work-related reasons and found a clinic that could provide complete care for the disorder—in Ohio, at a Cincinnati Children's Hospital clinic where they had to wait seven months for Kenneth's first appointment. 'There are so few pediatric GIs out there and so many children that need to be seen that you just have to wait in line,' says Kenneth's mother, Lauren Jones. 'That's the hardest thing to endure for a parent with a sick child who needs help right away.'"

As the nation's clinical workforce prepares for an increased patient volume through health reform CHGME funding will play an even larger role in a patient's access to care as our hospitals ensure that there are enough pediatricians and pediatric subspecialists trained to meet this new demand. CHGME has allowed children's hospitals to begin to address the large gap that exists between families' need for pediatric specialty care and the supply. In fact, free-standing children's hospitals that receive CHGME funding have accounted for 65 percent of the growth in pediatric specialty programs.

By strengthening children's hospitals' training programs and the nation's pediatric workforce, CHGME benefits all children, not just those treated at independent children's teaching hospitals. CHGME funds indirectly strengthen children's hospitals' roles as pediatric centers for excellence, the safety net for low-income children, and the leading centers of pediatric research. Children's hospitals are at the center of scientific discovery as a result of their strong academic programs supported by CHGME and advanced life-saving clinical research. Children's teaching hospitals' scientific discoveries have helped children survive diseases that were once fatal, such as polio and cancer. Furthermore, as a result of scientific research breakthroughs at children's teaching hospitals, children now can grow and thrive with disabilities and chronic health conditions, such as congenital heart disease, cystic fibrosis, cerebral palsy, juvenile diabetes, and spina bifida, and become economically self-supporting adults and valuable members of their communities.

CHGME is a sound investment. With full funding, CHGME will help to ensure a stable future for the nation's children's hospitals and the pediatric workforce. With that support, children's hospitals will continue to be centers for excellence and be able to provide the highest quality health care to all children.

Once again, thank you for your past support for this critical program. On behalf of N.A.C.H., and the Children's Hospital of Wisconsin, and the children and families we serve, I respectfully ask you to provide \$330 million for CHGME in FY 2011 to support the continued progress that has been made in CHGME. As the nation embarks on the implementation of the landmark health reform legislation, it is imperative that we have a strong pediatric workforce with a sufficient pool of specialists to meet the unique health care needs of all children.

The National Association of Children's Hospitals (N.A.C.H.) is the public policy affiliate of the National Association of Children's Hospitals and Related Institutions (NACHRI). N.A.C.H. is a trade organization of 140 children's hospitals and supports children's hospitals to address public policy issues that affect their ability to fulfill their missions to serve children and their families. N.A.C.H. works to strengthen the ability of children's hospitals and health systems to influence public policy makers, understand federal and state policy issues, advance access and quality of health care for all children, and sustain financially their missions of clinical care, education, research and advocacy.

Biography of Peggy Troy

Margaret "Peggy" Troy, MSN, RN, serves as the president and chief executive officer of Children's Hospital and Health System in Milwaukee, Wisconsin.

Prior to joining Children's Hospital and Health System, Troy served as chief operating officer of Methodist Le Bonheur Healthcare in Memphis, Tenn. Prior to her role as COO at Methodist, Troy was chief executive officer of Le Bonheur Children's Medical Center for three years. She also has nearly 20 years of leadership experience at Cook Children's Medical Center in Fort Worth, Texas.

Troy earned her bachelor's degree in Nursing from Marquette University in 1974. While attending Marquette, she served as a nurse intern at Children's Hospital of Wisconsin, the flagship of Children's Hospital and Health System. Troy also earned a master's in Nursing from DePaul University.

While in Texas, Troy received the Texas Nurse of the Year award for Maternal and Child Health and in 1991 she received the Helen Farabee Leadership award by the Texas Perinatal Association. In 2001 she received the Mental Health Association's Advocate of the Year award. She was also appointed by the Governor of Texas to serve on the statewide health coordinating council.

Troy has served on many boards including the board of directors for the Child Health Corporation of America where she was chairman of the audit and finance committee. She was appointed by the Governor of Tennessee to serve on the Health Services and Development Agency Board. She currently serves on the National Association of Children's Hospital and Related Institutions and on an advisory council for Child Health Corporation of America.

Peggy served on the United Way campaign cabinet and is a member of the Greater Milwaukee Committee. She was recently elected to the boards of directors of the Metropolitan Milwaukee Association of Commerce and Blood Center of Wisconsin. She will be this year's co-chair of UPAF Ride for the Arts.

Updated 3/10/10

Mr. OBEY. Thank you. The Committee will recess until 2:00.

AFTERNOON SESSION

WEDNESDAY, MAY 12, 2010.

TESTIMONY OF INTERESTED INDIVIDUALS AND
ORGANIZATIONS

Mr. OBEY. Good afternoon, everybody. The Committee will resume its sitting.

Mr. Rehberg, did you have anything you wanted to say?

Mr. REHBERG. No, let's get on.

Mr. OBEY. Okay. I am for that.

Our first witness this afternoon will be Eric Rose from the Alliance for Biosecurity. And as I said this morning, I am going to have to be very strict with the four-minute rule because otherwise people at the end will not get to testify, because we have another meeting at 4:00 p.m. and somebody is going to call a roll call on the House Floor, too, you can bet. So please proceed.

WEDNESDAY, MAY 12, 2010.

**CENTERS FOR DISEASE CONTROL AND PREVENTION,
NATIONAL INSTITUTES OF HEALTH**

WITNESS

ERIC A. ROSE, M.D., CO-CHAIR, ALLIANCE FOR BIOSECURITY

Dr. ROSE. Mr. Chairman and Members of the Subcommittee, I am Eric Rose, the CEO of Siga Technologies and Co-Chair of the Alliance for Biosecurity. It is a pleasure to be with you today to provide you with my impression of how the United States Government and specifically BARDA is handling a critical national security mission.

We at Siga develop novel biodefense countermeasures to treat and prevent serious infectious diseases. While many have criticized the perceived slow pace of development of critically needed novel defense countermeasures, our experience has been that the substantial Federal investment in biodefense is beginning to bear fruit less than seven years after BioShield enactment and less than four years after the creation of BARDA.

We at Siga have pursued the development of a treatment that has been sought for hundreds of years, namely an oral drug to cure smallpox. The United States has stockpiled enough smallpox vaccine for the entire Nation, but the vaccine cannot treat the potentially large number of symptomatic disease victims in the event of a surprise attack whose expected mortality rate would be 30 percent.

We are now producing commercial scale validation batches of our drug candidate which we hope will soon be added to the Strategic National Stockpile.

The Alliance for Biosecurity is a collaboration among pharmaceutical and biotechnology companies that is working in the public interest to improve prevention and treatment of biological threats. The H1N1 pandemic has given us all a better sense of how quickly biological threats can spread. Fortunately in that case, the consequences of mortality and morbidity were minimal.

Most large pharmaceutical companies have chosen not to develop biological countermeasures, while small biotechnology companies have become heavily engaged. These financially fragile enterprises must survive the so-called valley of death, the significant product development hurdles between basic research and procurement, in order to bring safe and effective medical countermeasures to the government for purchase.

Congress appropriated \$5,600,000,000 in 2003 to Project BioShield to fund potential countermeasure procurements, while three years later it created BARDA with a separate advance development budget to ensure a pipeline of novel, safe, effective and procurable countermeasures.

Our experience with BARDA leadership has been overwhelmingly positive. I have interacted with Dr. Lurie and Dr. Robinson and many others about the state of play for emerging biotech companies like ours and how their decisions affect the marketplace. They have been responsive and interested and are gaining traction in the organization to deliver on its critical mission.

We note that the December, 2008 report of the Congressionally established Commission on the Prevention of Weapons of Mass Destruction, Proliferation and Terrorism found that “it is more likely than not that a weapon of mass destruction will be used in a terrorist attack somewhere in the world by the end of 2013,” most likely a bio-weapon.

With respect to appropriations, we encourage that even in this challenging budget environment, the need to sustain and even strengthen BARDA’s advanced development funding is understood well.

However, the transfer of BioShield resources to shore up this funding is counterproductive to the Nation’s overall biodefense effort. This is because diversion of funds for acquisitions from BioShield clearly disincentivizes private investment in this sector at a time when increased private sector effort and funding is clearly critical.

We at the Alliance urge the Committee not to transfer additional dollars out of the BioShield reserve fund, and instead to maintain the fund balances as guarantees that future procurements will have sufficient resources available.

Let me stop there and invite your questions.

[Written statement by Eric A. Rose, M.D. follows:]

COVER PAGE

Written Testimony Submitted to the House of Representatives
Labor, Health and Human Services, and Education Appropriations Subcommittee
Regarding FY 2011 Funding for BARDA Advanced Research and Development

Submitted by:

Eric A. Rose, M.D., CEO and Chairman, Siga Technologies, New York, NY
and Co-Chair of the Alliance for Biosecurity, Washington, DC
on behalf of

The Alliance for Biosecurity (www.allianceforbiosecurity.org)
May 12, 2010, 2:00pm

Summary

The Alliance for Biosecurity respectfully submits testimony in support the Biomedical Advanced Research and Development Authority (BARDA) program within the Department of Health and Human Services (HHS) and urges a substantial increase in BARDA funding. These funds are required to close the gap between the FY2010 funding level of \$305 million and the estimated \$3.4 billion needed annually through FY 2015 to give BARDA a 90% chance of developing one successful medical countermeasure for each of the eight key bioterrorism threats facing the U.S. The Alliance also expresses its concern that continued transfers of funds out of the BioShield Special Reserve Fund (SRF) places the sustainability of this program in jeopardy.

Bioterrorism and emerging infectious diseases present an extraordinary and potentially grave threat to public health and national security. The development of medical countermeasures that can treat, mitigate and prevent biological agents are an essential component of national preparedness. Given the catastrophic consequences of a newly emerged infectious disease (e.g. SARS) or the intentional release of bioweapons (e.g. anthrax or smallpox) these medical countermeasures need to be developed, licensed and stockpiled well in advance of an emergency.

The federal government is essential in developing these medical countermeasures. The lack of a commercial market for these products means that without governmental involvement these life-saving products will not be developed. Congressional foresight combined with bipartisan and bicameral support for these efforts led to the establishment of BARDA. BARDA has both the statutory authority and administratively effective tools to meet this challenge. Indeed, initial federal investments during BARDA's start-up phase are beginning to deliver results. Unfortunately, however, thus far the federal investment in BARDA has not been commensurate with either the magnitude of the threat of bioterrorism and emerging infectious diseases, or the high costs associated with drug and vaccine development.

Despite the challenges associated with drug development the civilian population is far better protected today than it was in 2001 following the release of anthrax in the US Capitol and postal system. The Strategic National Stockpile, the repository for medical countermeasures, contains entirely new products to treat anthrax exposure including a first in-class monoclonal antibody, a new immune immunoglobulin that can be used to treat botulism poisoning and numerous other products that can prevent, mitigate or treat exposure to chemical nerve agents; biological agents, including smallpox and anthrax, and radiological agents.

The Alliance for Biosecurity is a collaboration among eleven private and public pharmaceutical and biotechnology companies that are working in the public interest to improve prevention and treatment of severe infectious diseases—particularly those diseases that present global security challenges. The Alliance promotes a stronger, more effective partnership between government, the biopharmaceutical industry, and other stakeholders in order to advance their shared goal of developing critically needed medical countermeasures.

We very much appreciate the Subcommittee's consideration of our views, and we stand ready to work with Subcommittee members and staff on this and other biosecurity matters.

Biosecurity is a Critical National Security Priority

The United States is engaged in an important national security effort to support the development and manufacture of new drugs, vaccines, and diagnostic tests needed to protect Americans from CBRN and emerging infectious disease threats. Currently, medical countermeasures for many of the agents of greatest concern do not exist. Until these medical countermeasures are developed, manufactured and stockpiled, our country will remain vulnerable to terrorist attacks.

As you know, BARDA is responsible for protecting Americans against chemical, biological, radiological and nuclear (CBRN) agents by supporting the advanced development and procurement of essential medical countermeasures, including medicines, vaccines and medical devices. Congress established two distinct mechanisms to fund these activities; advanced development to be funded by yearly appropriations as authorized in the Pandemic and All-Hazards Preparedness Act of 2006 and procurement to be funded using the Special Reserve Fund established in Project BioShield Act of 2004.

BARDA advanced research and development funding is essential to ensure that promising medicines and vaccines do not languish after early-stage research. The US government is the only purchaser of these products and therefore there is no commercial market for these products; as such, robust and consistent funding of BARDA advanced research and development is needed to ensure that the US has the medical countermeasures necessary to protect Americans. An independent analysis concluded that funding BARDA advanced development at \$3.4 billion annually would be required through FY 2015 to give BARDA a 90% chance of developing one successful medical countermeasure for each of the eight key bioterrorism threats facing the U.S.

The Alliance has consistently supported robust funding for medical countermeasure development and procurement through BARDA and the SRF. The Alliance recognizes the current budget constraints Congress faces; however, we are very concerned about the gap between the needed amount as stated above and the FY2010 funding level of \$305 million for BARDA. We urge your consideration of a substantial increase in funding for FY2011 to close this gap to ensure essential medicines and vaccines are developed.

The Alliance firmly believes that continued transfers of funds out of the BioShield SRF places the sustainability of this program in jeopardy. The original appropriation under Project BioShield was meant to be used over the course of 10 fiscal years. This reflected the length of time it takes to develop a drug or vaccine, as well as the need for a long term biodefense market. The Alliance requests that the committee follow the original legislative intent of Project

BioShield and use SRF monies solely for activities directly related to the advanced development and procurement of medical countermeasures.

Medical Countermeasures are Essential to Preparedness

The December, 2008 report of the Congressionally established *Commission on the Prevention of Weapons of Mass Destruction Proliferation and Terrorism* found that “it is more likely than not that a weapon of mass destruction will be used in a terrorist attack somewhere in the world by the end of 2013,” and that “terrorists are more likely to be able to obtain and use a biological weapon than a nuclear weapon.”

On January 26th, 2010, the WMD Commission issued its report card on the federal government’s progress in WMD prevention and preparedness. In the area of bioterrorism, which the Commission has characterized as the most urgent threat, the White House and Congress were given an “F”. In the Commission’s words,

“Especially troubling is the lack of priority given to the development of medical countermeasures—the vaccines and medicines that would be required to mitigate the consequences of an attack. Congress created the Biomedical Advanced Research and Development Authority Advanced Development Fund to promote the development of new vaccines, drugs, and production processes required to meet the modern threats from man-made and naturally occurring epidemics. The estimated cost of developing the medical countermeasures required to meet the threats identified by the Department of Homeland Security is \$3.4 billion a year for the next five years. Appropriation for FY 2010 is less than one tenth of that. In addition, there have been several attempts by the Administration and Congress to “raid” the BioShield Strategic Reserve Fund for programs not associated with national security. In *World at Risk*, the Commission unanimously concluded that bioterrorism was the most likely WMD threat to the world. The capability to deter and respond to bioterrorism depends upon the strength of all links in the biodefense chain. Virtually all links are weak and require the highest priority of attention from the Administration and Congress.”

These stark observations reflect the fact that bioterrorism represents one of the direst threats to national security, and that the federal government has not done nearly enough to prepare for it. Bioterrorism is on par with nuclear terrorism in terms of lethality, but far more likely given the lower technological thresholds to create and deploy a biological agent. Medical countermeasures must be created in order to reduce our vulnerability to this very real threat. For now, however, the United States remains vulnerable to biological threats, both because (1) many of the medical countermeasures that the US has identified as essential to procure have not yet completed development; and (2) the potential list of biological threats is growing, driven by the ongoing revolution in the life-sciences that opens doors to the development of new and potent bioengineered threats. Addressing threats posed by known and unknown bioterror pathogens, pandemic influenza, and other destabilizing emerging infectious diseases requires sustained investment and creative partnerships between government, industry, and other stakeholders. Already, there have been extraordinary advances achieved through government investment and partnership with industry with respect to preparedness for pandemic influenza. A similar

collective endeavor is not only critical to biosecurity, but it also presents opportunities to leverage cutting edge innovation in the biodefense space to advance and rapidly accelerate drug development for a broad range of emerging infectious diseases in the US and around the world.

Government Funding is Insufficient to Protect American Citizens

New drug development is an extraordinarily time and resource-intensive process, with considerable risk: 80% of all candidates that enter clinical trials fail to attain FDA approval. As a result, on average it requires 10-15 years and approximately \$800 million from start to finish to gain approval for one product'. The development of medical countermeasures is further complicated by limited commercial returns or no commercial market whatsoever. Thus the traditional pharmaceutical model of raising private capital for product research and development is extremely difficult, and often impossible.

Congress has recognized some of these challenges and addressed them by creating effective tools to meet the nation's biosecurity needs, including Project BioShield and BARDA within HHS.

Project BioShield is a federal program established in 2004, which provided special authorities to HHS to allow the *procurement and stockpiling* of medical countermeasures against the CBRN agents. Congress provided Project BioShield with a \$5.6 billion appropriation through FY 2013 for this purpose. Several critical medical countermeasures, including those for use against anthrax, radiological and nuclear agents, and botulinum toxin, have already been acquired with Project BioShield funds. Funding remains in Project BioShield that is currently unobligated. This is not surprising or unwarranted. Procurement using Project BioShield funds can only occur when medical countermeasures development has progressed sufficiently to warrant procurement.

BARDA was established in 2006 through the Pandemic and All-Hazards Preparedness Act (PAHPA) to address this problem. BARDA leads and coordinates MCM initiatives across the federal government and was set up to provide advanced development funding for promising medical countermeasures. Specifically, BARDA bridges the funding gap between early-stage research and the ultimate procurement of products for the national stockpile under Project BioShield. The gap between this early-stage research and BioShield procurement – often referred to as the “Valley of Death” – is where many promising technologies and products have languished as the result of scarce resources.

By partnering with private industry and providing financial support, BARDA can reduce the development risk entailed in medical countermeasure research, thereby helping to mitigate the disincentives associated with countermeasure development, and ultimately improving our national readiness posture with regard to a chemical, biological, radiological or nuclear attack.

BARDA was initially authorized at \$1.07 billion over three years, and Congress has provided \$781 million for BARDA since its creation in December 2006. The Subcommittee is to be commended for its efforts to improve our nation's preparedness by dedicating resources to this critical program, and the Alliance is deeply appreciative of the Subcommittee's support for this national security priority.

However, available data suggests that increased BARDA funding could significantly expedite medical countermeasure development. An independent analysis by the Center for Biosecurityⁱ estimated that \$14 billion through FY 2015 in advanced development funding for BARDA would be required to have a 90% chance of ultimately developing just one successful medical countermeasure for each of the eight biodefense requirements set forth in HHS's PHEMCE Implementation Planⁱⁱⁱ.

BARDA is an organization that appreciates the urgency of the challenge it confronts, and is making significant contributions to the development of new medical countermeasures against CBRN threats, pandemic influenza, and emerging infectious diseases. There is now an enormous opportunity to leverage BARDA's largely untapped potential. A level of BARDA funding more reflective of the magnitude of the threat of CBRN terrorism and emerging infectious disease would improve our nation's security against weapons of mass destruction, stimulate the biotech sector, drive biomedical science forward, and ensure our country's continued global leadership in this critical field. Increased funding would also take advantage of BARDA's potential as an engine of innovation to support development of new science, technology platforms, and accelerated development processes that could be applied to a range of medicines and vaccines against infectious diseases.

We thank you for your consideration, and we look forward to working with you and the Subcommittee to increase our country's preparedness against biological weapons. As you know the Secretary of HHS has requested an end-to-end review of the countermeasure enterprise. We look forward to the results of the review and its recommendations for improving the process and providing feedback to the Subcommittee on the review.

ⁱ DiMasi, J.A. et al, 2003. The Price of Innovation: New Estimates of Drug Development Costs. *Journal of Health Economics* 22, 151–185.

ⁱⁱ Matheny, J., Mair, M., and Smith, B. T. 2008. Cost/Success Projections for US Biodefense Countermeasure Development. *Nature Biotechnology*. 26:981-983.

ⁱⁱⁱ PHEMCE is the Department of Health and Human Services' Public Health Emergency Medical Countermeasure Enterprise Implementation Plan for Chemical, Radiological and Nuclear Threats.

Eric Rose, MD

Eric Rose is an academic physician and entrepreneur with interests in drug discovery, biodefense, clinical evaluative research and health policy. Since 2007 he is the Executive Vice President for Life Sciences at MacAndrews & Forbes and CEO of Siga Technologies, Inc., a developer of anti-viral drug directed at potential agents of bioterror. He was appointed in 2007 to the National Biodefense Scientific Board which advises the HHS Secretary on biodefense, influenza, and emerging diseases. In 2008, he assumed the chairmanship of the Department of Health Policy at the Mount Sinai School of Medicine. From 1994 through 2007, he served as Surgeon in Chief at New York-Presbyterian Hospital/Columbia and Chairman of the Department of Surgery at the Columbia University College of Physicians and Surgeons, where he held a distinguished professorship. An accomplished heart surgeon, researcher and entrepreneur, Dr. Rose grew one of the nation's premier departments of surgery while managing, investigating and developing complex medical technologies ranging from heart transplantation and novel approaches to Alzheimer's disease to bioterrorism. He has authored or co-authored more than 300 scientific publications and has received more than \$25 million in NIH support for his research. Dr. Rose pioneered heart transplantation in children, performing the first successful pediatric heart transplant in 1984, and has investigated many alternatives to heart transplantation, including cross-species transplantation and man-made heart pumps. Siga has received more than \$100 million in federal research support since he joined the company, developing anti-viral drugs for smallpox, dengue, and Lassa fever. He received both his undergraduate and medical degrees from Columbia University.

Mr. OBEY. Let me say that I think you will find me asking virtually no questions because if we take any time at all, people are not going to get done.

I thank you for coming.

Dr. ROSE. Sure. Thank you.

Mr. OBEY. Let me suggest that since we have a vote on that Members go vote and let's just keep the Committee running and that way I will go vote after you hurry back so we can avoid stiffing somebody. Okay?

Mr. MORAN. I think it is a series of votes, though. There are four votes, that is the problem.

Mr. OBEY. Oh, wonderful. Well, all right. In that case, we will go until we are dangerously near missing the vote. [Laughter.]

Next, Ronald Tankersley, American Dental Association.

WEDNESDAY, MAY 12, 2010.

NATIONAL INSTITUTES OF HEALTH

WITNESS

RONALD L. TANKERSLEY, DDS, PRESIDENT, AMERICAN DENTAL ASSOCIATION

Dr. TANKERSLEY. Good afternoon. I am Ron Tankersley, a practicing oral surgeon and President of the American Dental Association. On behalf of the ADA's 157,000 member dentists, thank you, Mr. Chairman and Members of the Subcommittee for the opportunity to comment on the 2011 appropriations for Federal dental programs.

The ADA last testified before the Committee in 2006. Since that time, many oral health programs have made great advances, but much remains to be done to help reduce oral disease and increase access to dental care for those with untreated disease.

Since 2005, the National Institute of Dental and Craniofacial Research has established research networks to answer the questions that private dentists face every day in their practices. These networks allow for the rapid translation of scientific advances to clinical practice.

The NIDCR is also leading the investigation into salivary diagnostics. This research indicates that there is a strong possibility that saliva can one day be used to screen for breast, prostate, oral and pancreatic cancer, as well as detect cardiovascular disease, drug usage and exposure to diseases like anthrax. As a diagnostic tool, this could dramatically reduce cost and invasive procedures.

However, the most common of the oral diseases, dental caries or tooth decay, remains the most prolific communicable disease in the world. Even though it is preventable, it is still a major problem. Childhood caries are epidemic among the under-served populations, especially Native Americans. The ADA urges the Committee to fund NIDCR at \$463,000,000 to continue its critical research.

The Committee's past support has allowed general dentists and pediatric dental residency programs to remain stable and strong. The new healthcare reform law adds funding for public health dental residencies. This could not have happened at a more opportune time because there are still three States with fewer than 10 pedi-

atric dentists and there are only 180 certified public health dentists in America.

The ADA recommends that training in pediatric and public health dentistry programs be funded at the authorized amount of \$30,000,000.

The ADA has said for many years that the Nation cannot drill and fill its way out of the epidemic of untreated dental disease.

Mr. OBEY. I thought you were getting into another subject there. [Laughter.]

Dr. TANKERSLEY. We think it is catchy.

But there are viable solutions for preventing disease through community water fluoridation, early applications of dental sealants and varnishes, and establishing dental homes for children, and last but not least, oral health literacy programs. These proven cost-effective measures can dramatically reduce oral disease.

The new healthcare law includes several provisions for prevention and research programs in the CDC's Division of Oral Health. The ADA recommends \$33,000,000 to fully fund the Division's State Infrastructure Grant Program, and also help communities establish or rebuild their community fluoridation systems for their water supplies.

Mr. Chairman, I would be remiss if I did not note the personal interest that you have taken to improve oral health in your State and in this Country. We appreciate your recognition of how funding for small clinics, local dental sealant projects, where Federal dental programs can improve oral health outcomes in the dental workforce.

You have been a wonderful champion for oral health in this Country and we will greatly miss you, and thank you for the opportunity to testify.

[Written statement by Ronald L. Tankersley, D.D.S. follows:]

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ADA American Dental Association®

**STATEMENT OF THE
AMERICAN DENTAL ASSOCIATION
TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES
ON
SUPPORT OF DENTAL AND ORAL HEALTH-RELATED PROGRAMS AT
THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
SUBMITTED BY
RONALD L. TANKERSLEY, D.D.S.
PRESIDENT
May 12, 2010
2:00-4:30 P.M.**

Washington Office: 1111 14th Street NW Washington DC 20005 (202) 898-2400

Summary

On behalf of the American Dental Association (ADA), President Ronald L. Tankersley, D.D.S., an Oral and Maxillofacial Surgeon from Newport News, VA will testify before the subcommittee on Labor, Health and Human Services, Education and Related Agencies on May 12 at 2 pm.

- The ADA supports the work of National Institute of Dental and Craniofacial Research (NIDCR) but also believes that more must be done to understand the social, behavioral and biological determinants of oral and dental diseases and their impact on dental care. Furthermore, while NIDCR's research has established a strong association between oral health and systemic health there is more to uncover. Therefore, the ADA recommends that the Committee fund the NIDCR at \$463 million to continue to advance its research agenda.
- The new "Training in General, Pediatric and Public Health Dentistry" health professions program calls for funding to support the development and operation of general practice, pediatric and public health dental residency training programs; provide educational assistance for students; enhance faculty development; and provide faculty loan repayment. The ADA recommends the Training in General, Pediatric and Public Health dentistry programs be funded at the authorized amount of \$30 million and that current appropriation levels for dental residencies be maintained.
- In 2008, the CDC's Division of Oral Health received 32 grant applications to help states build their dental departments. Unfortunately, the Division had only enough funding to support 16 states. The states that received grants have been able to plan, implement and evaluate a variety of oral health programs. The Division also has the authority to offer states and communities grants to establish or update community water fluoridation systems. The ADA recommends \$33 million to fully fund the Division's state infrastructure grant program and to help local communities establish or rebuild their community water fluoridation systems.
- The Maternal and Child Health Bureau has supported state and community health programs through grant funding that focus on improvements increasing the number of children receiving age one dental visits, expanding services to children with special health care needs, and increasing the number of children completing restorative treatment needs identified through sealant programs. The program currently only supports 20 states. The ADA recommends that this program be funded at \$8 million so that all 50 states can participate.

On behalf of the American Dental Association (ADA), which represents over 157,000 dentists, (more than 70 % of all dentists practicing in America) thank you, Mr. Chairman and members of the subcommittee for the opportunity to comment on FY 2011 appropriations for federal dental programs. I am Dr. Ronald Tankersley, a practicing oral surgeon and president of the ADA.

The ADA last testified before the Committee in 2006 advocating for federal programs that provide dental research and education, as well as oral health prevention and community-based access programs. Since that time, there have been many advances in oral health programs due in large part to the strong support provided by this committee. But there still remains much more to do to reduce oral disease and increase access to dental care.

Two questions often asked by Committee members are – how have federal dollars been used and what is the outcome of those expenditures? We will show in our testimony how the Committee's investment in federal dental programs directly impacts the delivery of dental care in America and improves the oral health of its citizens.

National Institute of Dental and Craniofacial Research

Since 2005, the National Institute of Dental and Craniofacial Research (NIDCR) has established three regional research networks relying on private practicing dentists to conduct clinical research to answer questions they face every day in treating their patients. To date, nearly 700 practitioner-investigators have enrolled over 30,000 patients in 16 studies. Study findings have improved clinical decision-making for treatment of early tooth decay, addressed post-operative sensitivity, how to choose the most appropriate dental materials and improved patient education. These networks are important as they allow for the rapid translation of scientific advances into clinical practice while generating much needed data to guide and evaluate the delivery of oral health care.

Salivary diagnostics continues to be an important research field for NIDCR. It is now believed that saliva can one day be used to diagnose breast, prostate, oral, and pancreatic cancer, as well as detecting cardiovascular disease, drug usage, and exposure to toxic molecules that may cause diseases like anthrax. Because saliva is easy to collect and poses none of the risks, fears, or "invasiveness" of blood tests or exposure to x-rays it holds a potential to be a remarkable cost and time-saver for patients. For example, NIDCR is currently supporting aggressive efforts to provide clinical validation of preliminary results that could result in a self-contained, portable diagnostic test for cardiovascular disease. In related work, salivary biomarkers are being evaluated to detect myocardial infarction in patients presenting with chest pain at emergency departments. Currently, patients believed to have suffered a heart attack are kept overnight so that blood can be drawn several times over a 24 hour period to determine if a heart attack has occurred.

NIDCR-funded investigators are also working as a consortium with more than 1,900 affected families from eight countries to find additional genes involved in the formation of cleft lips and palates. Their work will have considerable benefits internationally and domestically. According to the Centers for Disease Control and Prevention (CDC), in the United States, cleft lip and palate is the third most common birth defect. Health expenditures are approximately eight times higher in the first 10 years of life for children with these birth defects than for those without.

While the NIDCR has advanced the scientific understanding in these areas of dental research it is important to recognize that dental caries remains the most prolific communicable disease in the world and that early childhood caries is still epidemic in underserved populations. The ADA supports the work of NIDCR but also believes that more must be done to understand the social, behavioral and biological determinants of oral and dental diseases and their impact on dental care. Furthermore, while NIDCR's research has established a strong association between oral health and systemic health there is more to uncover. Therefore, the ADA recommends that the Committee fund the NIDCR at \$463 million to continue to advance its research agenda.

Training in General, Pediatric and Public Health Dentistry

Four years ago when we last testified before the committee, the Administration had proposed eliminating funding for the health professions' general practice and pediatric dental residencies. This committee not only restored the funding but as of this year has nearly doubled their appropriation. That support has stabilized and increased the number of general residency programs to 554 in 2009.

Pediatric dental residency positions increased by 131 between 2005-2009. However, according to CDC data, tooth decay is on the rise among young children for the first time in 40 years, so we need to continue to increase the supply of general and pediatric dentists who treat children. Furthermore, there are 3 states that have fewer than 10 pediatric dentists. North Dakota and Vermont have eight and Wyoming has six.

The Patient Protection and Affordable Care Act (PPACA, P.L. 111-148), through a new authorization, calls for increasing the funding for these residency programs as well as fully funding public health dental residencies. Public health dentists are integral for monitoring the oral health status of communities; investigating public health problems; conducting epidemiologic and health services research; establishing and evaluating community-based prevention programs; developing policies to enhance and protect the public's oral health; educating and providing oral health information; mobilizing community partnerships; and assuring coordinated access for all Americans to appropriate prevention and treatment services.

Currently, there are only 180 board certified public health dentists in the country. As of last November, there are no dentists actively serving full-time within the Health Resources and Services Administration (HRSA) regional dental consultant billets. This prevents the agency from providing valuable full-time assistance to health centers. There are only 11 board certified public health dentists serving as state dental directors. Rebuilding the local, state and federal aspects of the dental public health infrastructure, which includes recruiting and retaining public health dentists, is key to implementing the prevention and wellness provisions of the PPACA.

The new "Training in General, Pediatric and Public Health Dentistry" health professions program also calls for funding to support the development and operation of dental training programs; provide educational assistance for students; enhance faculty development; and provide faculty loan repayment. Under the PPACA, academic dental institutions are now eligible for Predoctoral and Postdoctoral Training in Primary Care, Academic Administrative Units in Primary Care, and Faculty Development in Primary Care. The ADA recommends the Training

in General, Pediatric and Public Health dentistry programs be funded at the authorized amount of \$30 million and that current appropriation levels for dental residencies be maintained.

CDC's Division of Oral Health

The PPACA for the first time has provided vital funding for prevention and wellness programs. For oral health, the law calls for the CDC's Division of Oral Health to develop an oral health prevention education campaign, a research-based dental caries (tooth decay) disease management program, and a national dental sealant program, as well as updating national dental health studies. These provisions are especially important because of the increase in tooth decay and survey data that shows only one-third (33 percent) of mothers considered oral health a concern for their infants. Additional survey findings reported by the American Academy of Pediatric Dentistry found that just 14 percent of parents realized that tooth decay in children can ultimately lead to the need for a root canal – even in infants.

However, the data also revealed that oral health literacy campaigns can have a profound effect. 78 percent of the survey respondents agreed they would take their children to visit a pediatric dentist before their first birthday if they knew that the visit would result in better oral health as the children developed. Ensuring that parents receive such education can also result in cost savings. Studies show that dental costs for children who have their first dental visit before age one are 40 percent lower in the first five years than for those who do not see a dentist prior to their first birthday.

To address these concerns, the ADA has developed a National Health Literacy in Dentistry Action Plan. As part of that program, the ADA is developing an oral health literacy campaign that will educate the public, policy makers, dental professionals and other health care workers about the importance of good oral health. We believe that our efforts would be enhanced and more effective if CDC and other federal agencies could join with us in a public-private partnership.

To carry out these new and expanded prevention programs the CDC's Division of Oral Health will need to rely on state dental programs. In 2008, the CDC received 32 grant applications to help states build their dental departments. Unfortunately, the Division had only enough funding to support 16 states. The states that received grants have been able to plan, implement and evaluate a variety of oral health programs. For example, Arkansas increased its fluoridation rate from 49% to 64%, formed a state oral health coalition with 38 member organizations, instituted an oral health literacy program and funded a state-developed oral disease burden document identifying oral health disparities and unmet needs.

One of the easiest and most cost effective ways to reduce dental disease is through community water fluoridation, which has proven to be safe and effective in reducing dental decay in both children and adults by 30–50%. At a savings of about \$23–\$26 per person per year, this translates to national annual savings in dental treatment costs of more than \$4 billion per year. Currently, 27 states have met the national objective of having at least 75% of their population on public water systems receive optimally fluoridated water. The CDC Division of Oral Health is authorized to provide grants to communities to purchase water fluoridation equipment which would be used to increase the number of states that provide fluoridated water to 75% of their

citizens and support states that need to replace their aging equipment. More than 30 states have identified communities that need equipment upgrades. Other states, such as Louisiana, have unfunded mandates to fluoridate water systems. In Louisiana alone, additional funding for fluoridation equipment could extend fluoridation to more than 2 million people. The ADA recommends \$33 million to fully fund the Division's state infrastructure grant program and to help local communities establish or rebuild their community water fluoridation systems.

State Oral Health Workforce Program

Funding for state dental workforce grants has grown from \$2 million in 2005 to \$17.5 million today due to the Committee's support. This program has been highly popular and successful because it allows states flexibility to use funds in a variety of ways to increase access to oral health care in a manner that best matches their needs. As of 2009, over 25 states had received grants. Funding has been used to offer loan forgiveness to dental providers who practice in underserved areas, establish or expand dental facilities, set up mobile clinics, support dental residency programs, and establish teledentistry programs for distance-based dental education, among other projects. The ADA recommends that \$20 million funding be appropriated for this program.

Maternal and Child Health Oral Health SPRANS Program

Since 2003, the Committee has supported state and community oral health programs in the Maternal and Child Health Bureau (MCHB). State oral health programs have used the funding to better integrate oral health into state MCH programs and address MCHB performance measures to the benefit of women and children. The current grant program supports 20 States in building capacity to expand preventive and restorative oral health service programs for Medicaid and State Children's Health Insurance Program (SCHIP) eligible children, and other underserved children and their families. States specifically focus on improvements within one or more of the following three program areas:

- increasing the number of children receiving age one dental visits,
- expanding services to children with special health care needs, and
- increasing the number of children completing restorative treatment needs identified through sealant programs

The program is currently funded at \$3.2 million which allows each participating state a grant of approximately \$165,000. The ADA recommends that this program be funded at \$8 million so that all 50 states can participate

Patient Protection and Affordable Care Act

Mr. Chairman, the ADA was profoundly disappointed that the PPACA did not address improving dental coverage for children and adults eligible for Medicaid. In addition, while the PPACA calls for increasing Medicaid payments to physicians there is no such provision for dentists.

Data show that there is a direct relationship between the level of reimbursement and dentists' participation in Medicaid and the utilization of services by beneficiaries. Michigan's Healthy Kids Dental (HKD) program dramatically improved access in selected rural communities through a partnership between the state, the Michigan Dental Association and Delta Dental. Dentists in those counties are paid at Delta PPO rates. Under this program the participation of

dentists in Medicaid went from 20 percent to 90 percent. Over 2,000 additional dentists joined the program. The distance between providers was cut in half – making it easier for patients to access care. The typical dentist in the program added over 50 Medicaid-enrolled patients to his/her practice. The ADA believes that Medicaid programs like Michigan's HKD program should be expanded into both rural and urban areas.

We were very disappointed that the PPACA did not support this approach because as of 2007, the Centers for Medicare and Medicaid Services (CMS) reported that only 34 percent of the total eligible Medicaid population received dental care with less than 2 percent of the entire Medicaid expenditures going for dental care.

We fear that the situation is only going to get worse. Of the 50 states and the District of Columbia, only nine have what could fairly be called full dental Medicaid coverage for adults. Eighteen have what we consider a limited benefit package. Sixteen cover only emergencies. And eight states have no adult benefits at all. Michigan and Utah have recently eliminated adult services, and California curtailed its adult program to cover only pregnant women.

Furthermore, because the PPACA extends Medicaid eligibility to individuals in families with incomes up to 133 percent of the federal poverty level without addressing the funding issue, and without providing a basic adult dental benefit for existing or new Medicaid enrollees, Congress is essentially promising an insurance card without real access to oral health care.

Consequently, because the PPACA did not address improving access to dental care under Medicaid, the programs we discussed today under this Committee's jurisdiction become even more important for preventing oral disease and improving access to dental care. Therefore, we strongly urge the Committee to support our funding recommendations.

Mr. Chairman, this concludes my testimony. Thank you for the opportunity to address the Committee. I would be glad to answer any questions you might have.

**Ronald Tankersley, D.D.S.
ADA President**

Biography

Ronald L. Tankersley, who practices the dental specialty of oral and maxillofacial surgery in Newport News, Williamsburg and Hampton, Virginia, is president of the American Dental Association.

Dr. Tankersley served a four-year term on the ADA Board as the trustee from the Sixteenth District (North Carolina, South Carolina and Virginia.) His previous responsibilities with the ADA include serving as chairman of the Council on Dental Benefits, the Strategic Planning Committee, the Advisory Committee on the Code, the Diagnostic Coding Committee, the Standing Committee for Diversity, and the Dental Content Committee. Dr. Tankersley also served on the Future of Healthcare/Universal Coverage Taskforce.

During his term on the ADA Board, he served as Board liaison to the Dental Economics Advisory Group, the Committee on the New Dentist, the Council on Access, Prevention & Interprofessional Relations and the Council on Ethics, Bylaws & Judicial Affairs.

Dr. Tankersley is a past president of the Virginia Dental Association, Virginia Society of Oral and Maxillofacial Surgeons and Southeastern Society of Oral & Maxillofacial Surgeons.

He received his dental degree from the Medical College of Virginia School of Dentistry, where he also completed his residency in oral and maxillofacial surgery and is an Adjunct Professor of oral and maxillofacial surgery. Dr. Tankersley is a fellow of the American College of Dentists, the International Colleges of Dentists and the Pierre Fauchard Academy, an international honorary organization for dentists.

Dr. Tankersley and his wife, Gladys, reside in Newport News and are the parents of two children, Ken and Christie. Ken is a partner in the practice. Christie, a veterinarian, also resides in the area.

Mr. OBEY. Thank you very much. I appreciate your coming.
Next, Daniel Church, Hepatitis Appropriations Partnership.

WEDNESDAY, MAY 12, 2010.

CENTERS FOR DISEASE CONTROL AND PREVENTION

WITNESS

DANIEL CHURCH, ADULT VIRAL HEPATITIS PREVENTION COORDINATOR, MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH

Mr. CHURCH. Good afternoon, Chairman Obey and Members of the Subcommittee. I am Dan Church, the Adult Viral Hepatitis Prevention Coordinator for the Massachusetts Department of Public Health. I am here representing the Hepatitis Appropriations Partnership and the National Alliance of State and Territorial AIDS Directors.

Thank you for allowing me to address you today. I am here to speak to you about viral hepatitis. Viral hepatitis is a group of contagious liver diseases that can lead to life-long infection. There are over 5 million Americans chronically infected. It is the leading cause of liver disease, liver cancer and liver transplantation. It is also the most common cause of death in persons infected with HIV.

Unfortunately, two thirds of those infected do not know it because symptoms often don't occur until irreversible and potentially fatal liver damage has occurred. Chronic hepatitis B and C infections cost the United States approximately \$16,000,000,000 each year. Experts estimate that baby boomers account for two out of every three cases of chronic hepatitis C. If we do nothing to increase screening, the cost of these diseases will skyrocket and the American taxpayer will foot the bill as this cohort ages into Medicare in the next decade.

In Massachusetts, it is estimated that over 100,000 people are living with hepatitis C virus alone, most of whom are not aware of their infection. Since 2002, we have had 8,000 to 10,000 newly diagnosed cases of hepatitis C and 2,000 cases of hepatitis B reported to the Department of Public Health each year.

Since 2005, there has been an alarming increase in the numbers of people under the age of 25 being reported with chronic hepatitis C infection, indicating a new epidemic of disease largely due to heroin use among youth.

Despite this remarkably high disease burden both in Massachusetts and nationally, the only dedicated Federal funding for viral hepatitis is \$19,000,000 to CDC's Division of Viral Hepatitis. State health departments receive a total of \$5,000,000 that averages to \$90,000 per jurisdiction. This provides for only one staff person and no money for core prevention services such as hepatitis education, testing, vaccination for hepatitis A and B, surveillance and referral into medical management and care. I am that staff person in the Massachusetts Department of Public Health.

It is important to note that because of such minimal funding, CDC cannot implement a comprehensive prevention approach such as we have for other infectious diseases. Additionally, there is no funding for a national surveillance system so that we can understand the impact of these diseases and plan our prevention pro-

grams accordingly. We must rely on estimates from a national household survey from 2002 that did not include two highly impacted populations: homeless and incarcerated people.

The President's fiscal year 2011 budget proposes an almost \$2,000,000 increase for a total of \$21,000,000. While we laud this increase in a time of decreasing resources, it is insufficient to address the chronic diseases of this magnitude. We are asking for an increase of \$30,700,000 for total of \$50,000,000 for the Division of Viral Hepatitis. We are not asking for creation of a separate infrastructure, but rather to integrate into existing infectious disease programs such as HIV, STDs, and tuberculosis. Unfortunately, funding to support this integration is largely not available.

If we had the resources to test those at risk, the good news is that there are effective treatments to manage, and in the case of hepatitis C, to clear the virus. There are also new therapies for both hepatitis B and C in the pipeline. The Institute of Medicine recently issued a report, *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*.

I was a member of the panel that authored the report. The report attributes the lack of knowledge and awareness among the American public and healthcare providers, and large health disparities, to the lack of dedicated resources and high mortality rates. Without concerted efforts to respond, Americans will continue to be infected and fail to be identified, diminishing their quality of life and life expectancy. I urge you to invest in the prevention of these diseases so that we may one day control these burgeoning epidemics.

Thank you again for allowing me to speak with you today.

[Written statement by Daniel Church follows:]



Testimony Submitted by

Mr. Daniel Church
Epidemiologist/Viral Hepatitis Coordinator
Massachusetts Department of Public Health
Jamaica Plain, MA

Representing the Hepatitis Appropriations Partnership

Presented to the House Appropriations Subcommittee on Labor, Health and
Human Services, and Education

On the Fiscal Year 2011 budget including:
Centers for Disease Control and Prevention's Viral Hepatitis Prevention Program
and 317 Vaccine Program;
Health Resources and Services Administration's Community Health Centers and
Ryan White Program; and
Substance Abuse and Mental Health Services Administration

Wednesday, May 12, 2:00PM

As the Adult Viral Hepatitis Prevention Coordinator and epidemiologist in the Department of Public Health for the Commonwealth of Massachusetts, member of the Hepatitis Appropriations Partnership (HAP), and member of the National Alliance of State and Territorial AIDS Directors (NASTAD), I respectfully submit testimony for the record on behalf of HAP and NASTAD regarding federal funding for viral hepatitis in the FY2011 Labor, HHS and Education Appropriations legislation.

Viral hepatitis refers to a group of contagious liver viruses such as hepatitis B and C that are the leading causes of liver disease, liver cancer, liver transplantation and premature death in about 15,000 Americans annually. It is also the most common cause of death in Americans co-infected with hepatitis and HIV where as many as 25% of HIV-positive Americans are living with hepatitis C and 10% with hepatitis B. These diseases impose a chronic disease burden on Americans where over 5 million people are living with lifelong hepatitis B or C infection and 65-75% do not know it. Chronic hepatitis B and C infections cost the United States approximately \$16 billion each year. If left unchecked, the projected direct and indirect cost in the next decade of just the current hepatitis C epidemic—not including the hepatitis B epidemic—is \$85 billion. Especially given that baby boomers account for two out of every three cases of chronic hepatitis C, we know millions of Americans will be progressing in their liver disease and aging into Medicare within the decade. In addition, chronic viral hepatitis disproportionately affects racial and ethnic communities. African Americans have the highest rate of acute hepatitis B infections in the United States. African Americans and Hispanics have higher rates of hepatitis C infection than Caucasians. Finally, chronic hepatitis B is a leading cause in death in Asian Americans, with as many as 1 in 10 living with chronic hepatitis B.

Despite these burgeoning diseases and the ramifications of mortality and cost, viral hepatitis is one of the most underfunded and neglected diseases compared to other chronic diseases. States receive on average only \$90,000 annually for hepatitis prevention in adults. This provides for little more than one staff position—I am that staff person in the Massachusetts Department of Public Health. In the states, there is typically no funding for actual core public health services such as hepatitis outreach and education, screening and testing, or management and care. There is almost no funding for a surveillance system to capture the prevalence and incidence of these diseases. Because of this, there is no funding for community-based organizations to provide these and other services.

In Massachusetts, it is estimated that over 100,000 people are living with hepatitis C virus alone, most of whom have not been diagnosed and may not be aware of their infection. Since 2002, we have received reports of 8,000-10,000 newly diagnosed cases of chronic hepatitis C and 2,000 newly diagnosed cases of chronic hepatitis B each year. Since 2005, there has been a striking increase in the numbers of people under the age of 25 being reported with chronic hepatitis C infection, indicating a new epidemic of disease, largely due to heroin use among youth. Despite this remarkably high volume of morbidity and mortality, the public health response has been greatly constrained by limited awareness and subsequent low funding to support prevention, screening and medical management programs. The Massachusetts Department of Public Health has had a Viral Hepatitis Program in place since 1999. Currently, there is no state funding available directly for the program and we rely on federal funding—especially under the current economic climate of state budget cuts, state furloughs, and a diminishing and aging public health workforce. In addition, due to the limited funds for viral hepatitis, many hepatitis programs rely

on other funding streams such as HIV prevention funding and we have seen in the past year a significant decrease in funding to these programs as well. Given these funding challenges, states can do little to effectively prevent, control and manage the hepatitis epidemics in their jurisdictions.

The Institute of Medicine recently issued a report *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*. I was a member of the panel that authored the report and the report has attributed the lack of knowledge and awareness among the American public and health providers, the large health disparities, and the high mortality rates, to the lack of dedicated resources. Without concerted efforts to respond, Americans will continue to be infected and fail to be identified, diminishing their quality of life and life expectancy, as well as increasing labor and health costs, especially to Medicaid and Medicare.

As you craft the FY2011 Labor-HHS-Education Appropriations legislation, HAP and NASTAD urge you to consider the following critical funding needs of viral hepatitis programs:

Specific funding needs:

- We are requesting an increase of \$30.7 million for a total of \$50 million for the Centers for Disease Control and Prevention (CDC) Division of Viral Hepatitis (DVH);
- At least \$20 million for an adult hepatitis B vaccination initiative through the CDC Section 317 Vaccine Program;
- \$10 million for the Substance Abuse and Mental Health Services Administration (SAMHSA) to fund a project within the Programs of Regional and National Significance (PRNS) to reach persons who use drugs with viral hepatitis prevention services;

General funding needs:

- Increase funding for Community Health Centers to increase their capacity to serve people with chronic viral hepatitis and provide coordinated care;
- Increase funding for the Ryan White Program to adequately cover persons co-infected with HIV and viral hepatitis through additional case management, provider education and coverage of viral hepatitis drug therapies;
- Increase funding for the National Institutes of Health to support their *Action Plan for Liver Disease Research*

Specific funding needs

Division of Viral Hepatitis

FY2011 Request: \$30.7 million

The recently released Institute of Medicine (IOM) report, *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C* found that the public health response needs to be significantly ramped up. The IOM report attributes low public and provider awareness to the lack of public resources. Seventeen of the 22 recommendations in the report are specific to CDC DVH and state health departments. In order to implement these recommendations to improve the federal response, resources must be increased to health departments which are the backbone of the nation's public health system and coordinate the response to these epidemics.

President Obama's budget proposal includes a \$1.8 million increase for a total of \$21.1 million for the Division of Viral Hepatitis (DVH) at CDC, which is woefully insufficient to address infectious diseases of this magnitude. States and cities receive \$5 million total that averages to \$90,000 per jurisdiction. This is only enough for a single staff position and is not sufficient for the provision of core surveillance and direct care services. These services are essential to preventing new infections, increasing the number of people who know they are infected, and following up to help those identified to remain healthy and productive. We believe at a minimum funding to health departments should double to \$10 million. This increase is an important first step to making hepatitis prevention services more widely available. The expanded services should include hepatitis B and C education, counseling, testing, and referral in addition to delivering hepatitis A and B vaccine, and establishing a surveillance system of chronic hepatitis B and C.

Section 317 Vaccine Program

FY2011 Request: \$20 million

CDC identified funds through program cost savings in the Section 317 Vaccine Program, allocating \$20 million in FY2008 and \$16 million in FY2009 for purchase of the hepatitis B vaccine for high-risk adults. We commend CDC for prioritizing high-risk adults with this initiative, but relying on the availability of these cost savings is not enough. Additionally, this initiative does not support any supplies, infrastructure or personnel and health departments need additional funding to support the delivery of this vaccine. We request a continuation of \$20 million in FY2011 for an adult hepatitis B vaccination initiative through the CDC's Section 317 Vaccine Program.

Substance Abuse and Mental Health Services Administration

FY2011 Request: \$10 million

Persons who use drugs are disproportionately impacted by hepatitis B and C. The Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Substance Abuse Prevention (CSAP) and Center for Substance Abuse Treatment (CSAT) are uniquely positioned to reach populations at risk for hepatitis B and C. The existing infrastructure of substance abuse prevention and treatment programs in the United States provides an important opportunity to reach Americans at risk or living with viral hepatitis. We urge you to provide \$10 million to SAMHSA to fund a project within the Programs of Regional and National Significance (PRNS) to reach persons who use drugs with viral hepatitis prevention services.

General funding needs

Medical Management and Treatment

Access to medical care, available treatments and support services are critical to combat viral hepatitis mortality. While we are supportive of the President's efforts to modernize and expand access to health care, we also support increased funding for existing safety net programs. Low-income patients who are uninsured or underinsured can and do seek services at Community Health Centers (CHCs). Even for those with health insurance, treatment of viral hepatitis is complex and requires care coordination among many different providers and services. With the growing importance of CHCs as a safety net in providing frontline support for these individuals, we support increasing resources for CHCs to increase their capacity to serve people with chronic viral hepatitis.

Many low-income individuals co-infected with viral hepatitis and HIV can obtain services through the Ryan White Program, however only half of the state AIDS Drug Assistance Programs (ADAPs) are able to provide viral hepatitis treatments to co-infected clients. We urge you to increase Ryan White funding so states can provide adequate coverage for co-infected clients. Increased resources are also needed to improve provider education on viral hepatitis medical management and treatment, to cover additional case management for patients undergoing treatment and to allow more states to add viral hepatitis therapies and viral load tests to their ADAP formularies. While Ryan White providers offer lifesaving care to co-infected clients, they also have the expertise and infrastructure to provide limited services to viral hepatitis mono-infected clients.

Research

Finally, research is needed to increase understanding of the pathogenesis of hepatitis B and C. Further research to improve hepatitis B and C treatments that are currently difficult to tolerate and have low "cure" rates are also needed. The development of clinical strategies to slow the progression of liver disease among persons living with chronic infection, especially to those who may not respond to current treatment must be addressed. With effective vaccines against hepatitis A and B, it is important to continue to work towards the development of a vaccine against hepatitis C infection. The Liver Disease Branch, located within the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), has developed an *Action Plan for Liver Disease Research*. We request full funding for NIH to support the recommendations and action steps outlined in this *Action Plan for Liver Disease Research*. Until a vaccine for hepatitis C is available, enhanced prevention services for people at-risk are needed. These need to be evaluated and expanded to ensure that effective prevention programs are available nationally.

It is absolutely essential and urgent that we act aggressively to address the threat of viral hepatitis in the United States. In 2007 alone, the CDC estimated that 43,000 Americans were newly infected with hepatitis B and 17,000 with hepatitis C. Unfortunately, it is believed that these estimates of hepatitis B and C infections are just the tip of the iceberg. Most people living with hepatitis B and over three-fourths of people living with hepatitis C do not know that they are infected. It is estimated that the baby boomer population currently accounts for two out of every three cases of chronic hepatitis C. It is also estimated that this epidemic will increase costs by billions of dollars to our private insurers and public systems of health such as Medicare and Medicaid, and account for billions lost due to decreased productivity from the millions of American workers suffering from chronic hepatitis B and C.

As you continue to draft the FY2011 Labor-HHS Appropriations bill, we ask that you consider an increased federal response to viral hepatitis to diminish the costly impact of these diseases on our health care system and individual's health. A strong public health response is needed to meet the challenges of these costly infectious diseases. The viral hepatitis community welcomes the opportunity to work with you and your staff on this important issue.

DANIEL RICHARD CHURCH, MPH**Education**

Boston University School Of Public Health, Boston, MA May 1997
 MPH, Concentration: Epidemiology/Biostatistics

Connecticut College, New London, CT June 1993
 BA, Major: Psychology

Related Experience

Massachusetts Department of Public Health, Division of Epidemiology and Immunization
 Boston, MA March 1999 to Present

VIRAL HEPATITIS COORDINATOR/EPIDEMIOLOGIST:

- ◆ Coordinate the statewide viral hepatitis program including disease surveillance, research and evaluation initiatives, medical management services, counseling and testing programs, adult vaccination programs, educational campaigns for providers, patients and communities
- ◆ Write requests for responses, coordinate application review processes, manage contracts with funded agencies; write grant proposals
- ◆ Participate as a member of the Institute of Medicine's committee on viral hepatitis and liver cancer
- ◆ Oversee and participate in emergency preparedness activities
- ◆ Provide training to communities and professional groups on viral hepatitis epidemiology
- ◆ Coordinate statewide viral hepatitis advisory committee; serve as liaison with inter- and intra-departmental agencies regarding HCV prevention and control
- ◆ Respond to inquiries concerning infectious disease prevention and control; conduct outbreak or case investigations and implement control measures for communicable diseases
- ◆ Supervise appropriate staff

Fenway Community Health, Research and Evaluation Department
 Boston, MA January 1997 to March 1999

EPIDEMIOLOGY PROJECT MANAGER:

- ◆ Developed and implemented epidemiologic studies; supervised personnel and operations of research projects
- ◆ Designed, piloted and implemented behavioral and clinical data collection instruments; managed the analysis and presentation of project data
- ◆ Wrote grant proposals

SENIOR RESEARCH ASSOCIATE:

- ◆ Assisted in the development and implementation of protocols for community-based behavioral and epidemiologic research
- ◆ Provided HIV testing counseling and education; performed phlebotomy techniques and proper collection of other laboratory specimens

Boston University School of Public Health
Boston, MA

December 1996 to May 1998

TEACHING ASSISTANT:

- ◆ Tutored graduate students for Intermediate Epidemiology course with both individual and group sessions; assisted with the grading of papers and exams

Massachusetts Department of Public Health, HIV/AIDS Bureau
Boston, MA

July 1994 to January 1997

PROGRAM PLANNER:

- ◆ Wrote grant proposals and statewide epidemiological profiles
- ◆ Developed and implemented statewide and regional needs assessments
- ◆ Worked with committee to create, implement, and evaluate statewide skills building conference

Selected Publications and Abstracts

Institute of Medicine (2010). Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C. Washington, DC: The National Academies Press.

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Mr. OBEY. Thank you.
Let's keep going. Janel Wright, American Diabetes Association.

WEDNESDAY, MAY 12, 2010.

**CENTERS FOR DISEASE CONTROL AND PREVENTION,
NATIONAL INSTITUTES OF HEALTH, NATIONAL INSTI-
TUTE OF DIABETES, DIGESTIVE AND KIDNEY DISEASE**

WITNESS

**JANEL WRIGHT, NATIONAL ADVOCACY COMMITTEE CHAIR, AMER-
ICAN DIABETES ASSOCIATION**

Ms. WRIGHT. Mr. Chairman, distinguished Members of the Subcommittee, thank you for the opportunity to testify today.

As someone who has lived with diabetes for nearly 35 years, I am proud to represent the American Diabetes Association, nearly 24 million Americans with diabetes, and 57 million with pre-diabetes.

The Centers for Disease Control and Prevention have identified diabetes as a disabling, deadly epidemic on the rise. Between 1980 and 2007, its prevalence increased by 300 percent. Its total cost is over \$218,000,000,000 a year. During the four minutes I will be speaking to you, 12 Americans will be diagnosed with diabetes. Today, 55 Americans will go blind, 120 will enter end-stage kidney disease programs, and 230 will undergo an amputation because of diabetes.

If we do not take action to stop diabetes, one out of three of our children will face a future with diabetes. And for children in minority communities, it is close to one in two.

Despite these numbers, there is hope. Thank you for consistently funding vital HHS programs, including the National Institute of Diabetes, Digestive and Kidney Disease at the NIH and the CDC's Division of Diabetes Translation to help reduce the overwhelming burden of diabetes.

Because of this investment, our knowledge of the disease has been expanded and the critical work towards ending this epidemic can continue. As you consider fiscal year 2011 appropriations, we urge you to make diabetes a priority by increasing funding for these essential research and prevention programs proportionate to the magnitude of diabetes in our Country. And by doing so, changing the future and destiny of diabetes in America.

NIDDK continues to make major discoveries, including the ability to predict type 1 diabetes and new drug therapies for type 2. Because of advances in treatment, my hemoglobin A1c, which provides a snapshot of how well my disease is managed, went from 12.9 to 5.9. Each point I lower my A1c translates to a 40 percent better chance to avoid the devastating complications of diabetes.

There is still so much work to do. Scientists stand ready, willing and able to take diabetes research to the next level. The \$2,200,000,000 we are requesting for 2011 will allow the NIDDK to act on promising research opportunities and ultimately move us closer to the cure.

Stopping diabetes also means transforming new discoveries into new ways to prevent the disease. CDC's DDT works to eliminate

the preventable burden of diabetes. DDT has a proven record of success through community-based prevention programs, national diabetes surveillance, and translational research. But DDT is woefully under-funded.

The Association is requesting \$86,000,000 in 2011 funding for the DDT so these vital programs can reach more Americans at risk for the disease and its complications. DDT works to speed effective interventions to local communities. For example, NIDDK's Diabetes Prevention Program found modest weight loss prevented type 2 diabetes by 58 percent in patients at high risk. DDT moved this program into community settings and improved upon the trial, achieving the same astounding results for less than \$300 a year.

Congress recognized the importance of this program by authorizing the National Diabetes Prevention Program in the recently passed health reform law which, when funded, will expand this successful program. We acknowledge the Subcommittee's leadership in the implementation of the newly created Prevention in Public Health Fund, and respectfully request your support of \$80,000,000 in 2011 for implementation of the NDPP through the fund.

As you consider the 2011 appropriations for NIDDK and the DDT, we ask you to consider diabetes as an epidemic, growing at an astonishing rate, which will overwhelm our healthcare system with tragic consequences. To change this future, we must increase our commitment to research and prevention to reflect the burden diabetes poses both for us and for our children.

Thank you.

[Written statement by Janel Wright follows:]

Testimony of Janel Wright
National Advocacy Committee Chair, American Diabetes Association

Before the
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
(LHHS)
Committee on Appropriations, United States House of Representatives

Regarding
FY 2011 Appropriations for the
United States Department of Health and Human Services (HHS)
National Institutes of Health and the Centers for Disease Control and Prevention

Wednesday, May 12
2:00p.m. – 4:30p.m.

The Centers for Disease Control and Prevention (CDC) has identified diabetes as a disabling, deadly epidemic that is on the rise. Between 1990 and 2001, the prevalence of diabetes increased by 60 percent. The total cost of diabetes and its complications, including undiagnosed diabetes, pre-diabetes and gestational diabetes, to the U.S. healthcare system was an estimated \$218 billion in 2007.

The Association is grateful to the LHHS Subcommittee for consistently funding vital HHS programs, including the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention's (CDC) Division of Diabetes Translation (DDT) to help reduce the overwhelming costs of diabetes. It is because of this investment that our knowledge of the disease has been expanded and the critical work towards ending this epidemic can continue.

However, a greater federal investment in diabetes research at the NIDDK, and prevention, surveillance, control, and research work currently being done at the DDT is crucial for finding a cure and improving the lives of those living with, or at risk for, diabetes. Additionally, the National Diabetes Prevention Program (NDPP), a new program authorized through the Patient Protection and Affordable Care Act (P.L.111-148, SEC. 399V-3), is poised to cut dramatically the number of new diabetes cases in high-risk individuals.

With this in mind, for FY 2011, the Association is respectfully requesting \$2.209 billion for the NIDDK, an increase of \$252 million over the FY 2010 level, and \$86 million for the CDC's DDT, which represents a total increase of \$20 million.

Additionally, the Association is also requesting the Subcommittee's support for \$80 million for the implementation of the NDPP through the Prevention and Public Health Fund created in the Patient Protection and Affordable Care Act.

Testimony of Janel Wright, National Advocacy Committee Chair, American Diabetes Association
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Thank you for the opportunity to provide this testimony to the House LHHS Subcommittee. I am pleased to have the opportunity to submit testimony on behalf of the American Diabetes Association. As someone who has lived with diabetes for over thirty years, I am proud to be a representative of the 81 million American adults and children living with diabetes or pre-diabetes.

Every minute, three more people are diagnosed with the disease. While nearly 24 million Americans have diabetes today, that number is expected to grow to 44 million in the next 25 years if present trends continue. Every 24 hours, 230 people with diabetes will undergo an amputation, 120 people will enter end-stage kidney disease programs and 55 people will go blind from diabetes. Each and every day diabetes will cost our country over a half a billion dollars, yet, it is but a fraction of the costs that lie ahead unless we take action immediately to stop the march of this epidemic.

Thanks to you and your colleagues, Congress has consistently funded vital Department of Health and Human Services (HHS) programs to help reduce the overwhelming costs of diabetes. However, if we are to cure and prevent diabetes, there is much more to accomplish. Therefore, the Association urges the House LHHS Subcommittee to invest in research and prevention proportionate to the magnitude of the burden diabetes has on our country and, by doing so, to change the future of diabetes in America.

As the nation's leading non-profit health organization providing diabetes research, information and advocacy, the Association believes federal funding for diabetes prevention and research is critical, not only for the 24 million American adults and children (nearly 8 percent of the population) who currently have diabetes, but for the 57 million more with pre-diabetes. Of the 24 million, 6 million are unaware they have diabetes. Together, this means 25 percent of the U.S. population either has, or is at risk for developing, this serious disease. Federal funding for diabetes prevention and research efforts is critical to reversing this epidemic.

Diabetes is a chronic condition that impairs the body's ability to use food for energy. The hormone insulin, which is made in the pancreas, helps the body change food into energy. In people with diabetes, either the pancreas does not create insulin, which is type 1 diabetes, or the body does not create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. If left untreated, diabetes results in too much glucose in the blood stream. The majority of diabetes cases, 90 to 95 percent, are type 2, while type 1 diabetes accounts for five to ten percent of diagnosed cases. The complications of diabetes are widespread and serious. In those with pre-diabetes, blood glucose levels are higher than normal and taking action to reduce their risk of developing diabetes is essential.

The Centers for Disease Control and Prevention (CDC) has identified diabetes as a disabling, deadly epidemic that is on the rise. Between 1990 and 2001, the prevalence of diabetes increased by 60 percent. According to the CDC, one in three children born in the year 2000 is likely to develop the disease in their lifetime if current trends continue. This number is even greater among minority populations, where nearly one in two children will develop diabetes.

Additionally, type 2 diabetes, traditionally seen in older patients, is beginning to reach a younger population, due in part to the surge in childhood obesity. Approximately one in every 500 children and adolescents has Type 1 diabetes, and an alarming 2 million adolescents (or 1 in 6 overweight

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adolescents) aged 12-19 have pre-diabetes. The impact diabetes has on individuals and the health care system is enormous and continues to grow at a shocking rate. Diabetes is a leading cause of kidney disease, adult-onset blindness and lower limb amputations as well as a significant cause of heart disease and stroke. Since 1987, the death rate due to diabetes has increased by 45 percent. In that same period, death rates for heart disease, stroke and cancer have dropped.

In addition to the physical toll, diabetes also attacks our pocketbooks. A recent study by the Lewin Group found when factoring in the total costs of diabetes, including undiagnosed diabetes, pre-diabetes, and gestational diabetes, the total cost of diabetes and related conditions in the United States in 2007 was \$218 billion (\$18 billion for undiagnosed diabetes; \$25 billion for pre-diabetes; \$623 million for gestational diabetes). That year, medical expenditures due to diabetes totaled \$116 billion, including \$27 billion for diabetes care, \$58 billion for chronic diabetes-related complications, and \$31 billion for excess general medical costs. Indirect costs resulting from increased absenteeism, reduced productivity, disease-related unemployment disability and loss of productive capacity due to early mortality totaled \$58 billion. This is an increase of 32 percent since 2002. Thus, in just five years, the cost of diabetes increased by \$42 billion, or \$8 billion per year. In fact, approximately one out of every five health care dollars is spent caring for someone with diagnosed diabetes, while one in ten health care dollars is attributed to diabetes. Additionally, one-third of Medicare expenses are associated with treating diabetes and its complications.

Despite these numbers, there is hope. A greater federal investment in diabetes research at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), and prevention, surveillance, control, and research work currently being done at the Division of Diabetes Translation (DDT) at the CDC is crucial for finding a cure and improving the lives of those living with, or at risk for, diabetes. Additionally, the National Diabetes Prevention Program (NDPP), a new program authorized through the Patient Protection and Affordable Care Act (P.L.111-148, SEC. 399V-3), is poised to cut dramatically the number of new diabetes cases in high-risk individuals. In this vein, for FY 2011, the American Diabetes Association is requesting:

- \$2.209 billion for the NIDDK, an increase of \$252 million over the FY 2010 level. This additional funding will act to offset years of flat funding and inflation that caused cutbacks to promising research. It will also demonstrate Congress's commitment to science and research.
- \$86 million for the CDC's DDT, which represents a total increase of \$20 million for the DDT's critical prevention, surveillance and control programs. Expanded investment in the DDT will produce much larger savings in reduced acute, chronic, and emergency care spending.

Additionally, we are also requesting your support of \$80 million for the implementation of the NDPP through the Prevention and Public Health Fund created in P.L. 111-148.

NIH's National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

One of the 27 institutes housed at the NIH, NIDDK is poised to make major discoveries that could prevent diabetes, better treat its complications, and – ultimately – find a cure. Researchers at the NIH are working on a variety of projects that represent hope for the millions of individuals with both type 1 and type 2 diabetes. The list of advances in treatment and prevention is long, but it is

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important to understand much more can be achieved for people with diabetes with an increased investment in scientific research at the NIDDK.

Researchers have already learned a great deal about the biology of diabetes, and they now understand much more about the loss of islet cell function, which can affect the body's ability to regulate blood glucose levels. These discoveries have led directly to islet cell transplants and ongoing work to extend the life of transplanted cells. Thanks to research at the NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. The result is the ability to live healthier lives with diabetes. Because of these advances, my hemoglobin A1C, which provides a snapshot of an individual's blood glucose, went from 12.9% to 5.9%. This is a dramatic development for me and proof of the importance of NIDDK's work.

Recent discoveries at the NIDDK include the ability to predict type 1 diabetes risk, new drug therapies for type 2 diabetes, and the discovery of genetic markers that explain the increased burden of kidney disease among African Americans. The NIDDK funded the Diabetes Prevention Program, a multicenter clinical research trial that found modest weight loss through dietary changes and increased physical activity could prevent or delay the onset of type 2 diabetes by 58 percent.

While great strides have been made in diabetes research, there are many unanswered questions about the disease that merit further study. Towards that end, the NIDDK, in its role as the convener of the Diabetes Mellitus Coordinating Committee, a panel comprised of key HHS agencies, including the Food and Drug Administration and the CDC, and other federal partners such as the Department of Veterans Affairs, has developed a Diabetes Research Strategic Plan, to be finalized later this year, which outlines pressing diabetes research needs.

The plan identifies a number of areas for additional research. These include study into the intersection of genetic and environmental risk factors for diabetes in people of color in order to reduce the prevalence of the disease and its complications; identification of the key genetic factors that predispose or protect individuals against diabetes complications; and, study of the natural history of type 1 diabetes in order to foster the design of preventive therapy. Additional FY 2011 funding would allow the NIDDK to support this additional research in order to build upon past successes, improve prevention and treatment, and close in on a cure.

CDC's Division of Diabetes Translation (DDT)

The CDC's DDT works to eliminate the preventable burden of diabetes through proven educational programs, best practice guidelines and applied research. Funds appropriated to the DDT focus on developing and maintaining state-based Diabetes Prevention and Control Programs (DPCPs); supporting the National Diabetes Education Program (NDEP); defining the diabetes burden through the use of public health surveillance; and translating research findings into clinical and public health practice. Our request of an additional \$20 million will allow these critical programs at the DDT to reach more at risk Americans and help to prevent or delay this destructive disease.

The DDT's most important efforts are based within the DPCPs in all 50 states, the District of Columbia, and 8 other territories and are cornerstones of the Division's work. DPCPs work to not only reduce the incredible burden of diabetes, but to make certain the people they serve are fully aware of the disease and those with or at risk of developing diabetes are receiving the highest quality of care possible. Because they are community based, DPCPs are highly adaptable and capable of reaching those at greatest risk in a given area. DPCPs provide a vital infrastructure to coordinate

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diabetes prevention and control efforts, however, a severe lack of funding leaves DPCPs unable to reach all of those who could benefit from their work.

The Division also recognizes the role that education and awareness plays in the fight against diabetes. With this in mind, the DDT implements the NDEP in coordination with the NIDDK. The NDEP develops and disseminates information on the prevention and control of diabetes that serve as the guiding principles to improve the treatment and outcomes for people with diabetes and to prevent or delay the onset of diabetes. Another vital component of the DDT's efforts is the National Diabetes Surveillance System, which provides comprehensive diabetes data at the national, state, and local levels so analysts may better track the epidemic, and ensure the most effective use of taxpayer dollars.

The DDT also identifies important research findings, including the results of clinical trials and scientific studies, in order to pinpoint the public health implications of the research. These findings are applied in health care systems and within local communities. Areas of translational research include access to quality care for diabetes; cost-effectiveness of diabetes prevention and control activities; effectiveness of health practices to address risk factors for diabetes; and demonstration of primary prevention of type 2 diabetes. One example of a highly successful translational effort by the DDT is the Diabetes Prevention Program Initiative (DPPi), a structured lifestyle intervention modeled after the NIDDK's Diabetes Prevention Program (DPP) clinical research study. The DPPi is proving group lifestyle intervention can lower diabetes risk while being delivered in a cost effective way in a community setting, thus increasing the likelihood of improved outcomes for individuals at risk of developing the disease.

While the DDT has played an invaluable and instrumental role in fighting the diabetes epidemic, the reach of the Division could be significantly broader with additional FY 2011 funding. With an additional \$20 million, the DDT will be able to expand the reach of DPCPs in every state and territory. Given the dramatic decreases in funding for state and local health departments, supporting the work of the DPCPs to provide prevention and control guidelines and technical assistance to health officials in local communities is more critical than ever to ensure access to affordable and high-quality diabetes care and services.

Increased funding for the DDT will also allow the Division to build upon its work in reducing health disparities through vital programs such as the Native Diabetes Wellness Program, furthering the development of effective health promotion activities and messages tailored to American Indian/Native Alaskan communities. Additional resources will enable the DDT to expand its translational research studies that will lead to improved public health interventions. An excellent example of this work is the Search for Diabetes in Youth study; a collaboration between the DDT and the NIDDK designed to further clarify the impact of type 2 diabetes in youth so prevention activities aimed at young people can be improved.

The National Diabetes Prevention Program (NDPP)

Further studies of the DPP have shown this groundbreaking intervention can be replicated in community settings for a cost of less than \$300 per participant. With this in mind, the NDPP was authorized by the Patient Protection and Affordable Care Act of 2010 (P.L. 111-148). This new program will provide funding to the CDC to expand such evidence-based programs across the country. The Association acknowledges your leadership in the implementation of P.L.111-148,

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specifically the Prevention and Public Health Fund (SEC.4002), which provided \$15 billion in mandatory funding over the next 10 years for public health, wellness and prevention programs. We respectfully ask the committee to support \$80 million from the Fund for the NDPP.

The NDPP meets the goals of the Fund, which seeks to make a national investment in prevention and public health programs, both to improve the health of Americans and to rein in health care costs. The Urban Institute reported our country could save as much as \$190 billion over ten years by bringing the NDPP to scale. Implementation of the NDPP would allow the CDC to expand the reach of evidence-based community programs to identify, refer and provide those at high risk for diabetes with cost-effective interventions.

Conclusion

As you consider the Fiscal Year 2011 appropriation for the NIDDK and the DDT, we ask that you consider diabetes is an epidemic growing at an astonishing rate. If left unaddressed diabetes will overwhelm the healthcare system with tragic consequences. To change this future we need to increase our commitment to research and prevention in a way that reflects the burden diabetes poses both for us and for our children.

Increasing NIDDK funding to \$2.209 billion for next year opens the door to research opportunities that will both improve patient outcomes and reduce the economic cost of diabetes. Through the CDC's important programs at the DDT, we have the chance to drastically reduce the number of people with diabetes. Given the astounding costs of diabetes, the request of \$86 million for DDT is a modest investment in our future. Further, \$80 million from the Prevention and Public Health Fund for the implementation of the NDPP will not only improve the health of millions of Americans who are at high risk for diabetes, but it will also save health care costs in the long term.

Our fight against diabetes must be significantly expanded. Your continued leadership in combating this growing epidemic is essential in stemming the epidemic. Thank you for your commitment to the diabetes community and for the opportunity to submit this testimony. The Association is prepared to answer any questions you might have on these important issues.

Biography of Janel L. Wright

Ms. Wright currently serves as the Chief of Adjudications for the Division of Workers' Compensation for the Alaska Department of Labor, where she is responsible for administering the statewide workers' compensation adjudication program and is responsible for the legal processes and adjudicative functions of the Division of Workers' Compensation and the Alaska Workers' Compensation Board.

Ms. Wright is also an adjunct professor for the University of Alaska Anchorage's Center for Human Development, where she teaches a college course on legal and ethical issues for service providers of individuals with disabilities. Mr. Wright previously served as a staff attorney and Legal Director for the Disability Law Center of Alaska, where she advocated for the rights of individuals with disabilities under federal, state and municipal civil rights laws.

Ms. Wright is the National Advocacy Committee Chairperson for the American Diabetes Association, and a former member of the Association's Board of Directors. She is also member of the Association's Legal Advocacy Sub-Committee and a volunteer for its Alaska Affiliate. Ms. Wright currently serves as a member of the Discipline Committee for the Alaska Bar Association.

Ms. Wright has been recognized for her professional work and her extensive volunteer activities. Most recently, she was presented with the 2010 Denali Park Performance Award – Honorable Mention, by Governor Parnell to recognize excellence in public service and exceptional leadership qualities. In 2008, she was honored with the Carolyn Peter Volunteerism Award, which was presented to her by the Governor's Committee on Employment and Rehabilitation of People with Disabilities for being a positive force in ensuring rights for people with disabilities and a role model to others.

She has been given the American Diabetes Association's You Make a Difference Award to recognize her efforts in Alaska in ensuring insurance coverage for medical supplies to control and monitor diabetes. Ms. Wright has also been presented with the Justin Dart Freedom Award.

Ms. Wright received her Bachelor of Science in Economics from Allegheny College in Meadville, Pennsylvania, where she graduated Cum Laude in 1984. She received her Juris Doctorate from Ohio State University College of Law in 1987.

Mr. OBEY. Thank you very much.

And I hate to do this, but I have to go vote and we will be back as soon as the votes are over.

[Recess.]

Next, we have Scott Kneser from the American Heart Association. He is from a place called Wausau, Wisconsin. [Laughter.]

WEDNESDAY, MAY 12, 2010.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE, NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

WITNESS

SCOTT KNESER, VOLUNTEER, AMERICAN HEART ASSOCIATION

Mr. KNESER. Mr. Chairman and Members of the Subcommittee, I thank you for this opportunity to share my story and to advocate for increased funding for heart disease and stroke research, prevention and treatment.

As the Chairman has mentioned, my name is Scott Kneser. I am from Wausau, Wisconsin. I am a proud constituent of the Seventh Congressional District of Wisconsin, which is Chairman Obey's District. I am an accountant for the hospital, but more importantly, thanks to NIH-supported research, I am a heart disease survivor. I am also a volunteer for the American Heart Association, where I try to help other people like myself.

Chairman Obey, when you announced your retirement last week, you expressed your hope that you had made a difference during your 41 years in the House of Representatives. I am here to tell you that you have made a difference through your continued support of heart disease research and prevention programs. I am living proof of how your investment in NIH can lead to longer, more productive lives.

My battle with heart disease began in 1982 when I was diagnosed with hypertrophic obstructive cardiomyopathy, a genetic defect with a mitral valve prolapse and a heart murmur. In layman's terms, the main pumping chamber of my heart was enlarged and I had a valve that did not close properly. This condition caused blood to leak from my mitral valve and diminish my blood flow, creating a decrease in my activity level. In 2005, I became more symptomatic and experienced increased fatigue during normal activity like climbing stairs.

My doctors determined that I needed a type of surgery called septal myectomy. During this procedure, my surgeon went through my aortic valve and carved out the enlarged section of muscle on my septum which separates my heart's chambers to improve my blood flow.

Also at this time, I had an implanted cardio defibrillator placed in my chest to regulate my irregular heartbeats that were discovered during an EKG. This amazing device, a result of your investment in the NIH, keeps me alive by regulating my heartbeat. If I have more than five consecutive irregular heartbeats, the ICD shocks my heart back into a normal rhythm. I can even hold a

magnet over my ICD, which uploads the data on my heart. This data is then transferred to my cardiologist via the telephone lines.

Not long ago, the only solution to my condition was a heart transplant, but thanks to advances in medical research, I am recovered from my surgery and today I enjoy a 30 percent increase in my blood flow and my energy level has improved substantially. I can still run up and down the basketball court refereeing high school basketball games.

As a heart disease survivor, I have also benefitted from other advances such as color flow Doppler echocardiograms, which improve the non-invasive images of the heart and blood flow. And the gold standard for diagnosing heart problems, a heart catheterization, no longer requires an overnight hospital stay.

Despite these advances, there is no cure for heart disease and stroke. Heart disease remains our Nation's number one killer and stroke is still the number three cause of death. Thanks to NIH research, there are survivors like me. But to bring us closer to a cure, it is critical for Congress to increase funding for NIH heart research, now at only 4 percent of the budget, and stroke research, still at just 1 percent of the budget.

Also, Congress must increase funding for CDC's Heart Disease and Stroke Prevention Programs. Although heart disease and stroke can often be prevented, Americans need access to prevention programs, but that is not happening.

CDC spends just 16 cents per person on heart disease and stroke prevention. Moreover, more rural areas like my hometown of Wausau need increased access to automated external defibrillators to improve chances of sudden cardiac arrest victims surviving this particularly deadly form of heart disease.

Americans deserve better. Thank you for your time.

[Written statement by Scott Kneser follows:]

Heart Disease and Stroke. You're the Cure.



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AMERICAN HEART ASSOCIATION

Statement

Presented by

Scott Kneser

Volunteer

Wausau, Wisconsin

on

FISCAL YEAR 2011 APPROPRIATIONS

before the

**APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS-EDUCATION
U.S. HOUSE OF REPRESENTATIVES**

**The Honorable David Obey
Chairman**

**May 12, 2010
2:00 p.m.**

Summary of Recommendations:

National Institutes of Health---\$35.2 billion
National Heart, Lung, and Blood Institute---\$3.514 billion
National Institute of Neurological Disorders and Stroke---\$1.857 billion

Agency for Healthcare Research and Quality---\$611 million
Centers for Disease Control and Prevention---\$8.8 billion
Heart Disease and Stroke Prevention Program---\$76.221 million
WISEWOMAN---\$37 million
National Center for Health Statistics---\$162 million

Health Resources and Services Administration
Rural and Community Access to Emergency Devices Program---\$8.927 million

*"Building healthier lives.
Preventing heart disease,
diabetes and stroke."*

Over the past 50 years, significant progress has been made in the battle against cardiovascular disease (CVD) and stroke. The improved diagnosis and treatment has been remarkable – as has the survival rate. According to the National Institutes of Health (NIH), 1.6 million lives have been saved since the 1960s that otherwise would have been lost to CVD. Americans can expect to live on average four years longer due to the reduction in heart-related deaths.

However, one startling fact remains. Heart disease and stroke are still respectively the No. 1 and No. 3 killers of men and women in the U.S. Nearly 2,300 Americans die of CVD each day – one death every 38 seconds. CVD is a leading cause of disability and will cost our nation an estimated \$503 billion in medical expenses and lost productivity this year.

An estimated 81 million American adults now suffer from heart disease, stroke, and other forms of CVD. Risk factors such as obesity and diabetes are increasing. At the age of 40, lifetime risk for CVD is 2 in 3 for men and more than 1 in 2 for women.

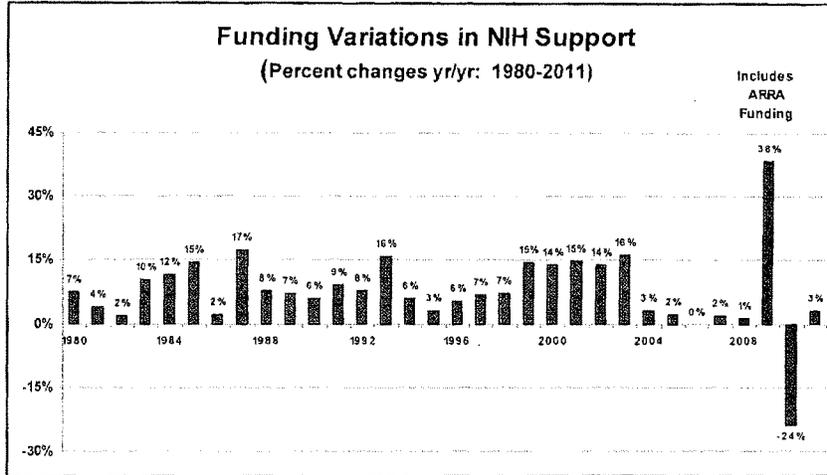
In the face of these staggering statistics, heart disease and stroke research, treatment and prevention programs remain woefully underfunded and overall funding for the NIH is too volatile to have the continuity of effort needed for the major breakthroughs that will redefine diseases, spur prevention and promote best care.

CVD is the No. 1 killer in each state and many preventable and treatable risk factors continue to rise. Yet, the Centers for Disease Control and Prevention (CDC) invests on average only 16 cents per-person a year on heart disease and stroke prevention. Specifically, CDC still provides basic implementation awards to only 14 states for its Heart Disease and Stroke Prevention Program and only 20 states are funded for WISEWOMAN – a heart disease and stroke screening and prevention program proven to be effective in reaching uninsured and under-insured low-income women ages 40 to 64 with a high prevalence of risk factors for these diseases.

Where you live could also affect if you survive a very deadly form of heart disease – sudden cardiac arrest (SCA). Only 10 states received funding in FY 2009 for Health Resources and Services Administration's (HRSA) Rural and Community Access to Emergency Devices Program designed to save lives from sudden cardiac death.

The American Heart Association applauds the Administration and Congress for providing hope to the 1 in 3 adults in the United States who live with the consequences of CVD through the enactment of the American Recovery and Reinvestment Act (ARRA).

The \$10 billion in funding for NIH and the \$650 million for Communities Putting Prevention to Work Program are wise and prudent investments that have provided a much needed boost to improve our nation's physical and fiscal health. Yet, these funds denote a one-time infusion of resources. Stable and sustained funding is imperative in FY 2011 to advance heart disease and stroke research, prevention and treatment. See the chart below.



FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION
Heart disease and stroke risk factors continue to rise, yet promising research opportunities to stem this tide go unfunded. Americans still die from CVD, while proven prevention programs and techniques beg for implementation. Clearly, now is the time to capitalize on the momentum achieved under ARRA to enhance research, prevention and treatment of America's No. 1 and most costly killer. If Congress fails to build on this progress, Americans will pay more in the future in lives lost and higher health care costs. Our recommendations below address these issues in a comprehensive and fiscally responsible manner.

| <u>Summary of Recommendations</u> | |
|---|------------------|
| National Institutes of Health | \$35.2 billion |
| National Heart, Lung, and Blood Institute | \$3.514 billion |
| National Institute of Neurological Disorders and Stroke | \$1.857 billion |
| Agency for Healthcare Research and Quality | \$611 million |
| Centers for Disease Control and Prevention | \$8.8 billion |
| Heart Disease and Stroke Prevention Program | \$76.221 million |
| WISEWOMAN | \$37 million |
| National Center for Health Statistics | \$162 million |
| Health Resources and Services Administration | |
| Rural and Community Access to Emergency Devices Program | \$8.927 million |

Capitalize on ARRA Investment for the National Institutes of Health (NIH)

NIH research has revolutionized patient care and holds the key to finding new ways to prevent, treat and even cure CVD, resulting in longer, healthier lives and reduced health care costs. **NIH invests resources in every state and in 90% of congressional districts. Each NIH grant generates on average 7 jobs.**

The American Heart Association Advocates: We advocate for a FY 2011 appropriation of \$35.2 billion for NIH – a \$4.2 billion increase over FY 2010, to capitalize on the momentum achieved under the ARRA investment to save lives, advance better health, spur our economy and spark innovation. NIH-supported research prevents and cures disease, generates economic growth and preserves the U.S. role as the world leader in pharmaceuticals and biotechnology.

Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment

Death rates for coronary heart disease fell 36% and nearly 34% for stroke from 1996-2006. These declines are directly related to NIH heart and stroke research, with scientists on the verge of exciting discoveries that could lead to new treatments and even cures. Landmark NIH research has shown that surgery and stenting are both safe and effective in preventing stroke. It has demonstrated that over-zealous blood pressure lowering and combination lipid drugs do not cut cardiovascular disease in adult diabetics more so than standard evidence-based care; nor does post-menopausal hormone therapy avert heart disease or stroke. And it has defined the genetic basis of risky responses to vital blood-thinners.

In addition to saving lives, NIH-funded research can cut health care costs. For example, the original NIH tPA drug trial resulted in a 10-year net \$6.47 billion reduction in stroke health care costs. The Stroke Prevention in Atrial Fibrillation Trial 1 produced a 10-year net savings of \$1.27 billion. But, in the face of such solid returns on investments and other successes, NIH still invests a meager 4% of its budget on heart research, and a mere 1% on stroke research.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)

Despite progress and promising research opportunities, there is no cure yet for CVD. As our population ages, the demand will increase for more and better ways to allow Americans to live healthy and productive lives despite CVD. Stable and sustained funding is needed to allow NHLBI to build on ARRA investments that provided grants to use genetics to identify and treat those at greatest risk from heart disease; hasten drug development to treat high cholesterol and high blood pressure; and create tailored strategies to treat, slow or prevent heart failure. Other important studies include an analysis of whether maintaining a lower blood pressure than currently recommended further reduces risk of heart disease, stroke, and cognitive decline. This information is critically important to ideally manage the burden of heart disease and stroke. Continued needed funding will allow for aggressive implementation of other initiatives in both the NHLBI general and cardiovascular strategic plans.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)

An estimated 795,000 Americans will suffer a stroke this year, and more than 137,000 will die. Many of the 6.4 million survivors face severe physical and mental disabilities, emotional distress and huge costs – a projected \$74 billion in medical expenses and lost productivity in 2010.

Stable and sustained funding is required for NINDS to capitalize on ARRA investments to prevent stroke, protect the brain from damage and enhance rehabilitation. This includes: (1) initiatives to determine whether MRI brain imaging can assist in selecting stroke victims who could benefit from the clot busting drug tPA beyond the three-hour treatment window; (2) assessing chemical compounds that might shield brain cells during a stroke; and (3) advance stroke rehabilitation by studying whether the brain can be helped to “rewire” itself.

Continued needed funding will also allow for assertive implementation of the NINDS Stroke Progress Review Group Report – a long-term, stroke research strategic plan. A variety of research initiatives have been undertaken, but more resources are needed to fully implement the plan. The FY 2010 estimate for NINDS stroke research is less than half of the expected need.

The American Heart Association Advocates: AHA supports an FY 2011 appropriation of \$3.514 billion for the NHLBI; and \$1.857 billion for the NINDS. These funding levels represent comparable increases to the Association’s overall recommended percentage increase for the NIH.

Increase Funding for the Centers for Disease Control and Prevention (CDC)

Prevention is the best way to protect the health of all Americans and reduce the economic burden of heart disease and stroke. However, effective prevention strategies and programs are not being implemented due to insufficient federal resources. Currently, CDC invests on average only 16 cents per-person each year on heart disease and stroke prevention.

For example, despite the fact that cardiovascular disease remains the No. 1 killer in every state, CDC’s Division for Heart Disease and Stroke Prevention still funds only 14 states to implement programs in healthcare, worksite and community settings to: (1) reduce high blood pressure and elevated cholesterol; (2) improve emergency response and quality care; and (3) end treatment disparities. Another 27 states receive funds for capacity building (planning). However, there are no funds for actual implementation and many of these states have been stalled in the planning phase for years – some for a decade. Nine states receive no prevention resources at all.

This CDC division also administers the WISEWOMAN program that screens uninsured and under-insured low-income women ages 40 to 64 in 20 states for heart disease and stroke risk. They receive counseling, education, referral and follow-up as needed. From 2000 to mid-2008, WISEWOMAN reached over 84,000 low-income women, provided more than 210,000 lifestyle interventions, and identified 7,647 new cases of high blood pressure, 7,928 new cases of high cholesterol, and 1,140 new cases of diabetes. Among those participants who were re-screened one year later, average blood pressure and cholesterol levels had decreased considerably.

The American Heart Association Advocates: AHA joins with the CDC Coalition in support of an appropriation of \$8.8 billion for CDC core programs, including increases for the Heart Disease and Stroke Prevention Program and WISEWOMAN. Within the total for CDC, AHA recommends \$76.221 million for the Heart Disease and Stroke Prevention Program, allowing CDC to: (1) add the nine unfunded states; (2) elevate more states to basic program implementation; (3) continue to support the remaining funded states; (4) maintain the Paul Coverdell National Acute Stroke Registry; (5) increase the capacity for national, state and local heart disease and stroke surveillance; and (6) provide additional assistance for prevention

research and program evaluation. AHA also advocates \$37 million to expand WISEWOMAN to additional states and screen more eligible women in funded states. And, we join the Friends of the NCHS in recommending \$162 million for the National Center for Health Statistics.

Restore Funding for Rural and Community Access to Emergency Devices (AED) Program

About 92% of SCA victims die outside of a hospital. However, prompt CPR and defibrillation, with an automated external defibrillator (AED), can more than double their chances of survival. Communities with comprehensive AED programs have achieved survival rates of about 40%. HRSA's Rural and Community AED Program provides grants to states to buy AEDs, train lay rescuers and first responders in their use and place AEDs where SCA is likely to occur. During year one, 6,400 AEDs were bought, and placed and 38,800 people were trained. Due to budget cuts, only 10 states received funds for this life-saving program in FY 2009.

The American Heart Association Advocates: For FY 2011, AHA advocates restoring HRSA's Rural and Community AED Program to its FY 2005 level of \$8.927 million.

Increase Funding for the Agency for Healthcare Research and Quality (AHRQ)

AHRQ develops scientific evidence to improve health and health care. Through its *Effective Health Care Program*, AHRQ supports research on outcomes, comparative effectiveness and appropriateness of pharmaceuticals, devices and health care services for diseases, such as heart disease, stroke and high blood pressure. Also, AHRQ's health information technology (HIT) plan is helping bring health care into the 21st century through more than \$300 million invested in over 200 projects and demonstrations since 2004. AHRQ and its partners identify challenges to HIT adoption and use; develop solutions and best practices; and produce tools that help hospitals and clinicians successfully integrate HIT. This work is a key component to health care reform.

The American Heart Association Advocates: AHA joins Friends of AHRQ in advocating for \$611 million for AHRQ to preserve its vital initiatives, boost the research infrastructure, reignite innovation, nurture the next generation of scientists and help reinvent health and health care.

CONCLUSION

Cardiovascular disease continues to inflict a deadly, disabling and costly toll on Americans. But, our recommended funding increases for NIH, CDC and HRSA outlined above will save lives and cut rising health care costs. The American Heart Association urges Congress to seriously consider our recommendations during the FY 2011 appropriations process. They represent a wise investment for our nation and the health and well-being of this and future generations.

SCOTT KNESER



Scott and his wife Sandy, reside in Wausau, Wisconsin. Scott has two step-sons, Patrick and Bryan. Scott was born in 1957 in Milwaukee, Wisconsin.

Currently, Scott works in finance with Aspirus Hospital in Wausau, Wisconsin. Scott earned his B.A. from Lakeland College in Sheboygan, Wisconsin. Scott has been a high school basketball referee since 2000. He has been a volunteer for the American Heart Association since 2005.

At the age of 25, in 1982, Scott was diagnosed with Hypertrophic Obstructive Cardiomyopathy with Mitral Valve Prolapse and a heart murmur. In layman's terms, Scott had an enlarged left ventricle with a valve that did not close properly. This condition caused blood leakage and poor blood flow.

In 2005, Scott became more symptomatic and experienced increased fatigue during normal activity. It was determined that Scott needed surgical intervention called a Septal Myomectomy. During this procedure, the surgeon went through the aortic valve and carved the enlarged section of muscle on the septum that was hindering his blood flow. At this time, Scott also had an implanted cardiac defibrillator placed in his chest.

Scott has recovered from his surgery and today enjoys a 30% increase in blood flow and his energy level has improved substantially. Scott is thankful for the support of his wife, family, friends, church and others. Scott continues to referee basketball during the winter months. In the warmer months, he enjoys golf, gardening, kayaking and biking with his wife.

Mr. OBEY. Thank you very much. I appreciate your coming. Glad you are doing so well.

Mr. KNESER. Thank you.

Mr. OBEY. I hope you have better luck with airplanes getting back. I usually do. [Laughter.]

Next, Landon King, American Thoracic Society.

WEDNESDAY, MAY 12, 2010.

AMERICAN THORACIC SOCIETY

WITNESS

LANDON KING, M.D., DIRECTOR, PULMONARY AND CRITICAL CARE MEDICINE, JOHNS HOPKINS SCHOOL OF MEDICINE

Dr. KING. Good afternoon. My name is Landon King. I am Director of Pulmonary and Critical Care Medicine at Johns Hopkins. I am here today representing the American Thoracic Society, whose 18,000 members are dedicated to preventing and fighting respiratory disease around the globe through research, education, patient care and advocacy.

I would like to particularly thank you, Mr. Chairman, for your leadership role in providing the historic biomedical research investment made through the American Recovery and Reinvestment Act. This investment is accelerating lifesaving research into respiratory diseases affecting millions of people.

I would like to illustrate how NIH-funded research turns medical advances that save people's lives by telling you about one patient that I treated in the medical intensive care unit in November. This 19 year old girl arrived in our ICU after becoming progressively ill at home for the preceding week. She developed worsening shortness of breath and required mechanical ventilation to stay alive.

In the ICU, she was diagnosed with H1N1 influenza. She required intravenous medication to support her blood pressure, as well as intravenous antibiotics to fight infection. She was on a ventilator in the ICU for several weeks and required additional weeks of hospitalization once she left the ICU.

Her care was managed throughout by dedicated teams of nurses, therapists and physicians. What ultimately improved this young girl's chances of survival was a new mechanical ventilation strategy that was less stressful on her lungs.

Several elements of her story are relevant to my testimony today. First, this young girl had H1N1 influenza, emphasizing the continued importance of a strong public health system. Second, respiratory failure of the type she experienced, called acute lung injury, can be caused by many things, including infection, drowning and traumatic injury, for example in traffic accidents. Threats from infectious disease or other exposures frequently cause illness or death because of the effect on the lungs.

Third, she's alive today as a result of the mechanical ventilation strategy developed through a National Heart, Lung and Blood Institute-funded clinical trial. In this study, pulmonary and critical care investigators identified that mechanical ventilation itself can damage the lung and through a multi-center clinical trial published in *The New England Journal of Medicine* demonstrated that sur-

vival was improved by 25 percent using a ventilator strategy distinct from traditional approaches.

Finally, despite the advances in ventilator management that saved this young girl's life and thousands of other patients each year, many more people are not so fortunate. Of the nearly 200,000 people per year who develop acute lung injury, approximately 75,000 people still die each year. By 2030, as a result of the aging population, it is estimated that the number of acute lung injury cases per year will increase to 335,000 and the number of deaths per year will increase to 147,000.

Despite groundbreaking research by NHLBI, NIGMS and other institutes, we do not have specific therapies other than mechanical ventilation to treat this type of respiratory failure. More investigation is essential to generate new approaches to therapy.

These examples are emblematic of respiratory disease in general. Chronic obstructive pulmonary disease, such as emphysema or chronic bronchitis, affects more than 12 million Americans and is the fourth leading cause of death in the U.S., the only one of the top four that has actually increased.

More than 22 million children and adults have asthma, with personal and public health costs of \$20,500,000,000 billion per year. It is estimated that more than 50 million Americans have breathing disturbances associated with sleep disorders, shown through NIH-funded investigation to increase strokes and death.

Beyond these, significant numbers of Americans have other lung diseases that cause illness and deaths every day.

Mr. Chairman, thanks in no small measure to the generous support of this Committee, the research and public health community continues to make advances against lung diseases. We urge this Committee to build on the biomedical research investment made through the ARRA to speed the discovery of more lifesaving treatments and cures.

Similarly, our Nation's public health and chronic and infectious disease prevention programs must be equipped to effectively translate NIH research into programs in chronic disease prevention, infectious disease control, and occupational safety and health research and training.

Thank you.

[Written statement by Landon King, M.D. follows:]



We help the world breathe
PULMONARY • CRITICAL CARE • SLEEP

*American Journal of Respiratory
and Critical Care Medicine*

*American Journal of Respiratory
Cell and Molecular Biology*

*Proceedings of the American
Thoracic Society*

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Director, Pulmonary and Critical Care Medicine
Johns Hopkins School of Medicine
Baltimore, MD

**STATEMENT OF
THE AMERICAN THORACIC SOCIETY
submitted to
THE HOUSE LABOR, HEALTH AND HUMAN SERVICES, AND
EDUCATION APPROPRIATIONS SUBCOMMITTEE
on the
FISCAL YEAR 2011 LABOR, HEALTH AND HUMAN SERVICES, AND
EDUCATION APPROPRIATIONS BILL**

May 12, 2010

**Department of Health & Human Services
National Institutes of Health
Centers for Disease Control & Prevention
Lung Disease**

SUMMARY: FUNDING RECOMMENDATIONS (in millions \$)

| | |
|---|-----------------|
| National Institutes of Health | \$35,000 |
| National Heart, Lung & Blood Institute | \$3,514 |
| National Institute of Allergy & Infectious Disease | \$5,395 |
| National Institute of Environmental Health Sciences | \$779.4 |
| Fogarty International Center | \$78.4 |
| National Institute of Nursing Research | \$163 |
| Centers for Disease Control and Prevention | \$8,800 |
| National Institute for Occupational Safety & Health | \$364.3 |
| Asthma Programs | \$70 |
| Div. of Tuberculosis Elimination | \$220.5 |
| Chronic Disease Prev. & Health Promotion: COPD | \$3 |
| Office on Smoking and Health | \$280 |
| National Sleep Awareness Roundtable (NSART) | \$1 |

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ATS 2010 • International Conference • May 14 – 19 • New Orleans, Louisiana

The American Thoracic Society (ATS) is pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview. The American Thoracic Society, founded in 1905, is an independently incorporated, international education and scientific society that focuses on respiratory and critical care medicine. With approximately 18,000 members who help prevent and fight respiratory disease around the globe, through research, education, patient care and advocacy, the Society's long-range goal is to decrease morbidity and mortality from respiratory disorders and life-threatening acute illnesses.

LUNG DISEASE IN AMERICA

Diseases of breathing constitute the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include chronic obstructive pulmonary disease (COPD), lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, asthma, and critical illness. The death rate due to COPD has doubled within the last 30 years and is still increasing, while the rates for the other three top causes of death (heart disease, cancer and stroke) have decreased by over 50%. The number of people with asthma in the U.S. has surged over 150% since 1980 and the root causes of the disease are still not fully known.

In recognition of the rising global burden of lung disease and the need for increased awareness and action to promote lung health, the ATS, in conjunction with the Federation of International Respiratory Societies, has declared 2010 to be the Year of the Lung. Throughout 2010, the ATS will be sponsoring a series of congressional briefings and other events to raise lung disease awareness.

National Institutes of Health

The ATS deeply appreciates the \$10 billion in supplemental funding provided for the NIH in the American Recovery and Reinvestment Act. This funding has sustained NIH support for groundbreaking research into diseases like COPD and asthma that affect millions of Americans. It is critical that this reinvestment in biomedical research is reinforced through annual budget increases that permit the NIH to respond to public health needs. **We ask the subcommittee to provide \$35 billion in funding for the NIH in FY2011.**

Despite the rising lung disease burden, lung disease research is underfunded. In FY09, lung disease research represented just 20.4% of the National Heart Lung and Blood Institute's (NHLBI) budget. Although COPD is the fourth leading cause of death in the U.S., research funding for the disease is a small fraction of the money that is invested for the other three leading causes of death. In order to stem the devastating effects of lung disease, research funding must continue to grow.

CRITICAL CARE

The burden associated with provision of care to critically ill patients is enormous, and is anticipated to increase significantly as the population ages. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a high priority, and the NIH should be encouraged and funded to coordinate investigation related to critical illness in order to meet this growing national imperative.

Centers for Disease Control and Prevention

In order to ensure that health promotion and chronic disease prevention are given top priority in federal funding, the ATS supports a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and ensure an adequate translation of new research into effective state and local public health programs. We ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including TB control to prevent the spread of drug-resistant TB, and occupational safety and health research and training. **The ATS recommends a funding level of \$8.8 billion for the CDC in FY2011.**

COPD

COPD is the fourth leading cause of death in the United States and the third leading cause of death worldwide, yet the disease remains relatively unknown to most Americans. COPD is the term used to describe the limitation in breathing due mainly to emphysema and chronic bronchitis. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease.

Today, COPD is treatable but not curable. The ATS feels that resources committed to COPD for research and education are not commensurate with the impact the disease has on Americans. According to the NHLBI, COPD costs the U.S. economy an estimated \$37 billion per year. We recommend that the subcommittee encourage NHLBI and other NIH institutes to devote additional resources to finding improved treatments and a cure for COPD. The ATS commends the NHLBI for its leadership on educating the public about COPD through the National COPD Education and Prevention Program. As this initiative continues, we encourage the NHLBI to maintain its partnership with the patient and physician community.

CDC also has a role to play in this work. To address the increasing public health burden of COPD, we encourage the creation of a CDC COPD program at the Center for Chronic Disease Prevention and Health Promotion, and request **an appropriation of \$3 million in FY11 for this program.** We are hopeful that the program will include development of a national COPD response plan, expansion of data collection efforts and creation of other public health interventions for COPD, and that the CDC be encouraged to add COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the National Health Information Survey (NHIS) and the Behavioral Risk Factor Surveillance Survey (BRFSS).

TOBACCO CONTROL

Cigarette smoking is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. The ATS congratulates the President and the Congress for enactment of the Family Smoking and Tobacco Prevention Act and looks forward to working to fully implement and fund this historic public health law. The CDC's Office of Smoking and Health coordinates public health efforts to reduce tobacco use. In order to significantly reduce tobacco use within five years, as recommended by the subcommittee in FY2010, the ATS recommends \$280 million in funding for the Office of Smoking and Health in FY2011.

PEDIATRIC LUNG DISEASE

Lung disease affects people of all ages. The ATS is pleased to report that infant death rates for various lung diseases have declined for the past ten years. In 2006, about one in five deaths in children under 1 year of age was due to a lung disease. It is also widely believed that many of the precursors of adult respiratory disease start in childhood. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

ASTHMA

The ATS believes that the NIH and the CDC must play a leadership role in assisting individuals with asthma. National statistical estimates show that asthma is a growing problem in the United States. Approximately 22.2 million Americans currently have asthma, including 7 million children. African Americans have the highest asthma prevalence of any racial/ethnic group. The age-adjusted death rate for asthma in the African-American population is three times the rate in whites. **The ATS recommends an FY2011 funding level of \$70 million for the CDC's asthma program.**

SLEEP

Sleep is an essential element of life, but we are only now beginning to understand its impact on human health. Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50-70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, lost work and school productivity, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. Despite the increased need for study in this area, research on sleep and sleep-related disorders has been underfunded. **The ATS recommends a funding level of \$1 million in FY11 to support activities related to sleep and sleep disorders at the CDC, including for the National Sleep Awareness Roundtable (NSART), surveillance activities, and public educational activities.** The ATS also recommends an increase of funding for research on sleep disorders at the Nation Center for Sleep Disordered Research (NCSDR) at the NHLBI.

TUBERCULOSIS

Tuberculosis (TB) is the second leading global infectious disease killer, claiming 1.8 million lives each year. It is estimated that 9-14 million Americans have latent tuberculosis. Drug-resistant TB poses a particular challenge to domestic TB control owing to the high costs of treatment and intensive health care resources required. Treatment costs for multidrug-resistant (MDR) TB range from \$100,000 to \$300,000. The global TB pandemic and spread of drug resistant TB presents a persistent public health threat to the U.S.

Despite declining rates, persistent challenges to TB control in the U.S. remain. Specifically: (1) racial and ethnic minorities continue to suffer from TB more than majority populations; (2) foreign-born persons are adversely impacted; (3) sporadic outbreaks/clusters occur, outstripping local capacity; (4) continued emergence of drug resistance threaten our ability to control TB; and (5) there are critical needs for new diagnostics, treatment and prevention tools.

In recognition of the need to strengthen domestic TB control, the Congress passed the Comprehensive Tuberculosis Elimination Act (CTEA, P.L. 110-392) in 2008. This historic legislation revitalized programs at CDC and the NIH with the goal of putting the U.S. back on the path to eliminating TB. The new law also authorizes an urgently needed reinvestment into new TB diagnostic, treatment and prevention tools. **The ATS, recommends a funding level of \$220.5 million in FY 2011 for CDC's Division of TB Elimination, as authorized under the CTEA,** and encourages the NIH to expand efforts, as requested under the CTEA, to develop new tools to reduce the rising global TB burden, including faster diagnostics, new therapies, and an effective vaccine.

FOGARTY INTERNATIONAL CENTER

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area of TB treatment and research. These training grants should be expanded and offered to all institutions. **The ATS recommends Congress provide \$78.4 million for FIC in FY2011, which would allow expansion of the TB training grant program from a supplemental grant to an open competition grant.**

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

The National Institute of Occupational Safety and Health (NIOSH) is the sole federal agency responsible for conducting research and making recommendations for the prevention of work-related diseases and injury. **The ATS recommends that Congress provide \$364.3 million in FY11 for NIOSH to expand or establish the following activities:** the National Occupational Research Agenda (NORA); tracking systems for identifying and responding to hazardous exposures and risks in the workplace; emergency preparedness and response activities; and training medical professionals in the diagnosis and treatment of occupational illness and injury.

CONCLUSION

Lung disease is a growing problem in the U.S. It is this country's third leading cause of death. The level of support this subcommittee approves for lung disease programs should reflect the urgency illustrated by these numbers. The ATS appreciates the opportunity to submit this statement to the subcommittee. Please contact Nuala Moore, Sr. Legislative Representative, at NMoore@thoracic.org, or 202.296.9770 for more information.

Landon Stuart King, M.D.
Associate Professor of Medicine
Director, Pulmonary and Critical Care Medicine
Johns Hopkins School of Medicine
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Baltimore, MD 21205
Phone: 443-287-3343; Lsking@jhmi.edu

Education/Training

| | | | |
|------|------|----------|--|
| 1989 | M.D. | Medicine | Vanderbilt University School of Medicine |
| 1982 | B.A. | History | Wake Forest University |

Positions and Employment

| | |
|--------------|--|
| 1983-1989 | Medical Student, Vanderbilt University School of Medicine |
| 1986-1988 | Research Fellow, Vanderbilt Center for Lung Research |
| 1989-1990 | Intern, Osler Medical Service, Johns Hopkins University |
| 1990-1992 | Resident, Osler Medical Service, Johns Hopkins University |
| 1992-1993 | Assistant Chief of Service, Instructor, Department of Medicine, Johns Hopkins University |
| 1993-1997 | Fellow, Division of Pulmonary and Critical Care Medicine, Dept. of Medicine, Johns Hopkins University |
| 1993-1996 | Post-doctoral Fellow, Laboratory of Peter Agre, MD, Professor of Medicine and Biological Chemistry, Johns Hopkins University |
| 1997-2003 | Assistant Professor of Medicine, Johns Hopkins University |
| 2000-2003 | Assistant Professor of Biological Chemistry, Johns Hopkins University |
| 2003- | Associate Professor of Medicine, Johns Hopkins University |
| 2003- | Associate Professor of Biological Chemistry, Johns Hopkins University |
| 2004 | Interim Director, Division of Pulmonary and Critical Care Medicine, Johns Hopkins University DOM |
| 2005-Present | Director, Division of Pulmonary and Critical Care Medicine, Johns Hopkins University DOM |

Other Experience and Professional Memberships

| | |
|-----------|---|
| 1992 | American Thoracic Society |
| 2004 | American Society of Biochemistry and Molecular Biology |
| 1999-2003 | Director of Education and Fellow Recruitment |
| 2005- | Director, Division of Pulmonary and Critical Care Medicine |
| 2005-2006 | Chair, Nominating Committee, Respiratory, Cell and Molecular Biology Nominating Committee, ATS 2005 |
| 2005- | <i>Ad hoc</i> Reviewer, National; American Heart Association |
| 2008-2010 | Chair, Research Advocacy Committee, ATS 2008-2009 |
| 2009- | Member, Health Reform Rapid Response Team (HRRRT), ATS |

Honors

| | |
|-------|---|
| 1982 | Wake Forest: <i>Magna cum laude</i> ; <i>Phi Beta Kappa</i> ; <i>Omicron Delta Kappa</i> ; Mortar Board; Carswell Scholar; Atlantic Coast Conference Academic Award |
| 1989 | Vanderbilt: Justin Potter Medical Scholarship; <i>Alpha Omega Alpha</i> ; Rudolph H. Kampmeier Award in Medicine |
| 1992 | Johns Hopkins University Daniel Baker Award |
| 1997 | Certificate of Merit, Young Investigators Day |
| 1997 | Department of Medicine Fellow Teaching Award |
| 2006- | Member, American Society of Clinical Investigation |
| 2007- | Member, <i>Clinical and Translational Science</i> Editorial Board |
| 2009 | David Levine, MD Excellence in Mentoring Award, Johns Hopkins University School of Medicine |
| 2009 | Member, Editorial Board, <i>American Journal of Respiratory and Critical Care Medicine</i> |
| 2009 | Chair, Research Advocacy Committee, American Thoracic Society |

Mr. OBEY. Thank you very much.
 Next, Neil Bressler, American Academy of Ophthalmology.

WEDNESDAY, MAY 12, 2010.

**NATIONAL INSTITUTES OF HEALTH, NATIONAL EYE
 INSTITUTE**

WITNESS

DR. NEIL BRESSLER, WILMER EYE INSTITUTE, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE; AMERICAN ACADEMY OF OPHTHALMOLOGY

Dr. BRESSLER. Mr. Chairman, Subcommittee Members, thank you for the opportunity to appear before you today in support of appropriations for the National Institutes of Health and the National Eye Institute.

My name is Neil Bressler and I am the James P. Gills Professor of Ophthalmology at Johns Hopkins University. I currently serve as Chief of the Wilmer Eye Institute's Retina Division, but I also chair the FDA Ophthalmic Devices Panel and chair the Data and Safety Monitoring Committee, which oversees all intramural clinical trials by the National Eye Institute.

And I have been the recipient of many NIH grants to chair large scale multi-center clinical trials, most recently, a comparative effectiveness study conducted at more than 50 clinical centers by the Diabetic Retinopathy Clinical Research Network.

This network confirmed just two weeks ago a treatment breakthrough for saving the vision of tens of thousands of people in the United States each year with a common diabetic eye disease. And I am pleased to be here testifying on behalf of the American Academy of Ophthalmology, the world's largest organization of eye physicians and surgeons.

It is particularly appropriate, Mr. Chairman, to discuss vision and preventing blindness today since May is Healthy Vision Month, a designation to elevate vision as a health priority for the Nation. We need our vision to work, to read, to drive, to distinguish the faces in this room.

The Academy and the vision community commends Congress for \$10,400,000,000 in NIH funding in the ARRA, as well as fiscal year 2009 and 2010 funding increases that enabled the NIH to keep pace with biomedical inflation after six previous years of flat funding that resulted in a 14 percent loss of purchasing power.

The Academy supports a fiscal year 2011 NIH funding level of \$35,000,000,000, which would result in NEI funding at almost \$800,000,000. This funding level would increase the level of grants available to researchers, maintain the momentum of the research I am describing, and leverage the investment that Congress has already made in the NIH and the NEI through ARRA funding to allow us to continue to make breakthroughs which reduce blindness throughout the world.

The recent treatment breakthroughs which are having a huge impact on reducing vision impairment and blindness from these common eye diseases suggests that this is not the time for a less-than-inflationary increase that nets a loss in NEI's purchasing

power, which was previously eroded by 18 percent in fiscal years 2003 through 2008.

The baseline funding in fiscal years 2009 and 2010 has also enabled the NEI to fund key research networks that are studying such issues as the genetic basis of glaucoma, the second leading cause of blindness. And as I mentioned, the NIH just issued a press release only two weeks ago announcing the publication of this comparative effectiveness study which confirmed that a new treatment for swelling of the retina from diabetes, the main cause of central vision loss in people with diabetes, which can affect as many as 30 percent of people who have had diabetes for more than 20 years, and affects their ability to read or drive, the study showed that these eye injections of a new medication, combined with laser, nearly 50 percent of the people who received this treatment had substantial vision improvement, and fewer than 5 percent lost vision.

The unprecedented level of fiscal year 2009 to 2010 vision research funding is moving our Nation that much closer to preventing blindness and to restoration of vision. With an overall NIH funding level of \$35,000,000,000 and an NEI funding level of almost \$800,000,000, the vision community can accelerate these efforts and reduce healthcare costs, maintaining productivity, causing independence, and ensuring quality of life.

In closing, I would just like to summarize and encourage the Subcommittee to increase the funding level of the NIH to \$35,000,000,000 or at a minimum increase the NEI funding by at least 3.2 percent in fiscal year 2011 in order to continue the momentum of vision-saving research in the United States. Not working today to stave off debilitating eye disease will have a huge and grave economic and social repercussion for America's future.

Thank you very much.

[Written statement by Neil Bressler, M.D. follows:]



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Federal Affairs Department

Hearing on Fiscal Year 2011 Budget Priorities for Labor, Health and Human Services,
Education, and Related Agencies Appropriations
Before
The Subcommittee on Labor, HHS,
Education and Related Agencies
May 12, 2010
2pm

Testimony by Neil Bressler, MD
Wilmer Eye Institute at the John Hopkins University School of Medicine
Baltimore, Maryland
On Behalf of the American Academy of Ophthalmology

The American Academy of Ophthalmology requests Fiscal Year (FY) 2011 NIH funding at \$35 billion, which would result in NEI funding at \$795 million. This funding level would increase the level of grants available to researchers, maintain the momentum of research, and leverage the investment that Congress has already made in NIH and NEI.

**AMERICAN ACADEMY OF OPHTHALMOLOGY
TESTIMONY IN SUPPORT OF INCREASED
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)
AND THE NATIONAL EYE INSTITUTE (NEI)
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
APPROPRIATIONS SUBCOMMITTEE OF THE
U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS
May 12, 2010**

Thank you for the opportunity to appear before you today in support of appropriations for the National Institutes of Health (NIH) and the National Eye Institute (NEI). My name is Neil Bressler, and I am The James P. Gills Professor of Ophthalmology at the Johns Hopkins University School of Medicine. I currently serve as Chief of the Wilmer Eye Institute's Retina Division. I also Chair the FDA Ophthalmic Devices Panel, and chair the Data and Safety Monitoring Committee which oversees all intramural clinical trials by the National Eye Institute, and have been the recipient of many NIH grants to chair large scale multicenter clinical trials, most recently a comparative effectiveness study conducted at more than 50 clinical centers by the Diabetic Retinopathy Clinical Research Network; this network which confirmed just two weeks ago a treatment breakthrough for saving the vision of people with a common diabetic eye disease, and I am pleased to be here testifying on behalf of the American Academy of Ophthalmology, the world's largest organization of eye physicians and surgeons.

It's particularly appropriate, Mr. Chairman, to discuss vision and preventing blindness today as May is Healthy Vision Month, a designation to elevate vision as a health priority for the Nation. We need our vision to work, read, drive, and distinguish faces in this room. The Academy and the vision community commends Congress for \$10.4 billion in NIH funding in the American Recovery and Reinvestment Act (ARRA), as well as FY2009 and FY2010 funding increases that enabled NIH to keep pace with biomedical inflation after six previous years of flat funding that resulted in a 14 percent loss of purchasing power. The Academy supports a fiscal year 2011 NIH funding level of \$35 billion which would result in NEI funding at \$795 million. This funding level would increase the level of grants available to researchers, maintain the momentum of research, and leverage the investment that Congress has already made in NIH and NEI through ARRA funding to allow us to continue to make breakthroughs which reduce blindness throughout the world.

In June and July of 2009, Congress spoke volumes in passing S. Res 209 and H. Res 366, which acknowledged NEI's 40th anniversary and designated 2010-2020 as *The Decade of Vision*, in which the majority of 78 million Baby Boomers will turn 65 years of age and face greatest risk of aging eye disease. I was personally proud that the resolutions recognized that the NEI has been a leader in clinical research, and specifically referenced the series of trials that I chair through the Diabetic Retinopathy Clinical Research Network. The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as macular degeneration, glaucoma, diabetic retinopathy or cataracts. This is expected to grow to more than 50 million Americans by the year 2020. The economic and societal impact of eye disease that I see every day is increasing not only due to the aging population, but due to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease such as diabetes.

The recent treatment breakthroughs which are having a huge impact on reducing vision impairment and blindness from these common eye diseases suggests that this is not the time for a less-than-inflationary increase that nets a loss in NEI's purchasing power, previously eroded by 18 percent in fiscal years 2003 through 2008. Even with increases in baseline NEI appropriations in FY2009 and FY2010, the NEI is still catching up with this loss in purchasing power. Past NEI-funded basic and translational research has resulted in treatments and therapies to slow the progression of vision loss and restore vision for Americans of all ages and races. The growing economic and societal costs of vision impairment and eye disease are substantial, and adequately funding NEI is a cost-effective investment in our nation's vision health.

I would also like to point out that the NEI's research addresses the preemption, prediction and prevention of eye disease through basic, translational, epidemiological and comparative effectiveness research which also address the top five NIH priorities, as identified by Dr. Collins: genomics, translational research, comparative effectiveness, global health, and empowering the biomedical enterprise. The NEI received \$175 million in ARRA funding which resulted in 333 ARRA-related awards, the majority of which reflect investigator-initiated research that funds new science or accelerates ongoing research. Several examples of this research include:

- Using a recently discovered biomarker to develop an early detection method of the advanced stage of age-related macular degeneration, a leading cause of vision loss in the United States;
- Developing a clinical treatment for diabetic retinopathy (DR) that uses stem cells from the patient's own blood to repair damaged vessels in the eye;
- Evaluating existing data on the effectiveness of various treatment options for primary open angle glaucoma which disproportionately affects African Americans and Latinos.

The baseline funding increases in FY2009 and FY2010 have also enabled the NEI to fund key research networks that are studying such issues as:

- The genetic basis of glaucoma, the second leading cause of preventable blindness;
- The risk, diagnosis, and treatment of neuro-ophthalmic disease, such as visual dysfunction due to increased intracranial pressure and thyroid eye disease ; and
- As I mentioned, the NIH just issued a press release only 2 weeks ago announcing the publication of a comparative-effectiveness study which confirms a new treatment for swelling of the retina from diabetes, the main cause of central vision loss in people with diabetes, which can affect as many as 30% of people who have had diabetes for at least 20 years and affect the ability to read, drive, work, and distinguish faces. This study shows that eye injections of a medication, often in combination with laser, results in better vision than laser treatment alone, the standard care for the past 25 years. Nearly 50% of patients who received this new treatment experience substantial visual improvement and fewer than 5% experience substantial vision loss. Diabetic retinopathy is the most common cause of vision loss in working-age Americans, and the investment by Congress to the NIH to make studies such as these possible is an example of the huge, successful impact that these funding increases can have on the quality of life and productivity of America.

The unprecedented level of FY2009-2010 vision research funding is moving our nation that much closer to the prevention of blindness and restoration of vision. With an overall NIH funding level of \$35 billion and an NEI funding level of \$794.5 million, the vision community can accelerate these

efforts, thereby reducing healthcare costs, maintaining productivity, ensuring independence and enhancing quality of life.

If Congress does not increase FY2011 NIH funding above the President's request, it is even more vital to improve upon the proposed 2.5 percent increase for NEI. The NIH budget proposed by the Administration and developed by Congress during the very first year of the Congressionally-designated *Decade of Vision* should not contain a less-than-inflationary increase for NEI due to the enormous challenges it faces in terms of the aging population, the disproportionate incidence of eye disease in fast-growing minority populations and the visual impact of chronic diseases such as diabetes. If Congress is unable to fund NIH at \$35 billion in FY2011 (NEI level of \$794.5 million) and adopts the President's proposal, the 2.5 percent increase in funding must be increased to at least an inflationary level of 3.2 percent to prevent any further erosion in NEI's purchasing power. NEI funding is an especially vital investment in the overall health, as well as the vision health, of our nation. We have examples of great successes as a direct result of your increased funding previously; this track record shows that research from the NEI can ultimately delay, save and prevent health expenditures by avoiding vision impairment and blindness, especially those associated with the Medicare and Medicaid programs, and is therefore a cost-effective investment.

In closing, I would just like to summarize and encourage the Subcommittee to increase the funding level of the NIH to \$35 billion or at a minimum, increase NEI funding by at least 3.2 percent in FY2011 in order to continue the momentum of vision saving research in the United States. Missed opportunities in eye and vision research will translate into increased government dependence and a decreased quality of life for many aging members of the baby boom generation. I see this everyday in my work as a retina specialist and as a leader of NIH-sponsored clinical trials designed to reduce blindness from many common eye diseases. Not working today to stave off debilitating eye diseases will have huge and grave economic and social repercussions for America's future.

Thank you for your consideration.

ABOUT THE AMERICAN ACADEMY OF OPHTHALMOLOGY

The American Academy of Ophthalmology is a 501c (6) educational membership association. The Academy is the largest national membership association of Eye M.D.s with more than 27,000 members, over 17,000 of which are in active practice in the United States. Eye M.D.s are ophthalmologists, medical and osteopathic doctors who provide comprehensive eye care, including medical, surgical and optical care. More than 90 percent of practicing U.S. Eye M.D.s are Academy members.

Neil M. Bressler, MD
The Retina Division, Wilmer Eye Institute (Department of Ophthalmology),
Johns Hopkins University School of Medicine, Baltimore, Maryland, USA

Dr. Bressler graduated from the Johns Hopkins University School of Medicine in 1982, followed by an ophthalmology residency at Harvard Medical School's Massachusetts Eye and Ear Infirmary in 1986. He returned to join the faculty at the Wilmer Eye Institute at Johns Hopkins University School of Medicine, where he is currently Chief of the Retina Division and has an endowed chair as the inaugural James P. Gills Professor of Ophthalmology.

His main research interests have been collaborative efforts in clinical trials of common retinal diseases, including age-related macular degeneration and diabetic retinopathy, having chaired several NIH-sponsored and industry-sponsored multicenter randomized clinical trials. Currently as Chair of the NIH-sponsored Diabetic Retinopathy Clinical Research Network, he has extensive involvement regarding guidelines, policies, protocol development and implementation to facilitate Network operations in an open and transparent fashion. The Network priority initiatives include involvement of both community-based and university-based practices and collaboration with industry in a way that maintains academic integrity and optimal clinical trial performance and recently published a treatment breakthrough resulting in substantially better vision for people with diabetes in a government sponsored comparative effectiveness study. He also chairs the National Eye Institute's Data and Safety Monitoring Committee for intramural clinical trials, and is Chair of the FDA Ophthalmic Device Panel.

Beyond ophthalmology, he chairs, the Johns Hopkins University School of Medicine's Committee on Outside Interests, including financial conflicts of interest. As a member of the Board of Trustees for the Interlochen Center for the Arts in Michigan, he also shares responsibility for an entity which engages and inspires people worldwide through excellence in educational, artistic and cultural programs for the arts.

Mr. OBEY. Thank you.
Next, Wanda Burns, American Cancer Society Cancer Action Network.

WEDNESDAY, MAY 12, 2010.

**NATIONAL INSTITUTES OF HEALTH, NATIONAL CANCER
INSTITUTE**

WITNESS

**WANDA BURNS, RN, AMERICAN CANCER SOCIETY CANCER ACTION
NETWORK**

Ms. BURNS. Chairman Obey and Members of the Subcommittee, thank you for the opportunity to appear before you this afternoon to testify in support of the National Institutes of Health and National Cancer Institute. My name is Wanda Burns and I am from Niles, Ohio, a town just outside of Youngstown.

I am here today on behalf of the American Cancer Society Action Network, and my late sister-in-law Cindy. Cindy died from ovarian cancer in 2008 and I appear here today to honor her fight against cancer. I have been a registered nurse for 30 years, and in that time have seen first-hand the results of the tremendous progress we have made thanks to research in preventing, detecting and treating cancer, and better managing symptoms and side effects to improve patient quality of life.

Part of my nursing career has been in the hospice study, so I am also keenly aware that far too many people facing the disease, our cancer-fighting tools for early detection, treatment, and care remain limited. Ovarian cancer lacks a screening test to aid in the early diagnosis and treatment that is essential to survive. The majority of cases are diagnosed at a distant stage when the cancer has spread and the five-year survival rate in those cases drops to only 31 percent.

Cindy, sadly, was one of those cases. She discovered a protrusion on her abdominal wall in early January, 2004 and was diagnosed with cancer a few weeks later. By that time, Cindy's cancer had metastasized to her colon and diaphragm. According to statistics, Cindy's life expectancy was 19 months.

We were fortunate that Cindy's oncologist was able to help her find and enroll her in a clinical trial sponsored by the National Cancer Institute which took place at the Cleveland Clinic. While conventional chemotherapy failed and offered Cindy little help and hope, the clinical trial offered an additional course of treatment and an additional 45 months of life. Her participation in these clinical trials gave all of us hope. More importantly, it gave us precious additional time together as a family.

I am so pleased to tell you that Cindy beat the odds and enjoyed nearly five rewarding years of life after her late stage diagnosis, which included being there to see her only son get married. This meant the world to Cindy and to the entire family.

But research progress does not happen overnight, though we would wish it could. Cindy enrolled in one particular clinical trial at Cleveland Clinic in 2005, a trial that had actually initiated in 2001 and just concluded earlier this year. This trial, which took

just under 10 years to complete, evaluated a combined therapy regimen for treating ovarian cancer.

After being invited to testify, I checked in with Cindy's gynecological oncologist and learned that the results from the clinical trial are very promising. It is clinical trials such as this that give healthcare providers, patients, family and friends hope. Clinical trials are important to all of us, for no one knows what our personal futures hold.

Cindy's story and the countless stories of other cancer patients make clear that sustained funding for cancer research is critical to maintain and build on the progress we are making every day. The clinical trials that gave us treasured years with Cindy and gave Cindy countless special moments like being at her son's wedding, would not have happened absent support from the National Institutes of Health National Cancer Institute.

The NIH and NCI support life-saving research at the Cleveland Clinic, 64 NCI Cancer Centers and multiple other institutions in oncology practice settings across the country. Knowing that funding for this research is secure gives us all hope.

For this reason, I am requesting on behalf of the American Cancer Action Network that the National Institutes of Health receive a budget of \$35,000,000,000 in fiscal year 2011, including \$5,800,000,000 for the National Cancer Institute.

Thank you, Mr. Chairman, for the opportunity to testify.

[Written statement by Wanda Burns, R.N. follows:]



FY 2011 Public Witness Hearing

May 12, 2010

House Subcommittee on Labor – HHS – Education Appropriations

Statement of Wanda Burns, RN

Appearing on Behalf of the

American Cancer Society Cancer Action Network

Chairman Obey and Members of the Subcommittee:

Thank you for the opportunity to appear before you this afternoon to testify in support of the National Institutes of Health and National Cancer Institute. My name is Wanda Burns and I am from Niles, Ohio, a town just outside of Youngstown. I am here today on behalf of the American Cancer Society Cancer Action Network and my late sister-in-law, Cyndi. Cyndi died from ovarian cancer in 2008; I appear here today to honor her fight against cancer.

I have been a registered nurse for 30 years, and in that time have seen firsthand the results of the tremendous progress we have made, thanks to research, in preventing, detecting and treating cancer and better managing symptoms and side effects to improve patient quality of life. Part of my nursing career has been in the hospice setting, so I am also keenly aware that for too many people facing the disease, our cancer fighting tools for early detection, treatment and care remain limited.

Ovarian cancer lacks a screening test to aide in the early diagnosis and treatment that is essential to survival. The majority of cases are diagnosed at a distant stage when the cancer has spread, and the five year survival rate in those cases drops to only 31%. Cyndi sadly was one of those cases. She discovered a protrusion on her abdominal wall in early January 2004, and was diagnosed with cancer a few weeks later. By that time, Cyndi's cancer had metastasized to her colon and diaphragm. According to statistics Cyndi's life expectancy was 19 months.

We were fortunate that Cyndi's oncologist was able to help her find and enroll her in a clinical trial sponsored by the National Cancer Institute which took place at the Cleveland Clinic. While

conventional chemotherapy failed and offered Cyndi little hope, the clinical trial offered an additional course of treatment and an additional 45 months of life.

Her participation in these clinical trials gave all of us hope. More importantly, it gave us precious additional time together as a family. I am so pleased to tell you that Cyndi beat the odds and enjoyed nearly five rewarding years of life after her late-stage diagnosis, which included being there to see her only son get married. This meant the world to Cyndi, and to the entire family.

But research progress does not happen overnight, though we all wish it could. Cyndi enrolled in one particular clinical trial at the Cleveland Clinic in 2005 – a trial that had actually initiated in 2001 and just concluded earlier this year. This trial, which took just under ten years to complete, evaluated a combined therapy regimen for treating ovarian cancer. After being invited to testify, I checked in with Cyndi's gynecological oncologist and learned that the results from the clinical trial are very promising. It is clinical trials such as this that give healthcare providers, patients, their family and friends HOPE. Clinical trials are important to all of us for no one knows what our personal futures hold.

Cyndi's story and the countless stories of other cancer patients make clear that sustained funding for cancer research is critical to maintain and build on the progress we are making every day. The clinical trials that gave us treasured years with Cyndi, and gave Cyndi countless special moments like being at her son's wedding, would not have happened absent support from the National Institutes of Health and National Cancer Institute.

The NIH and NCI support lifesaving research at the Cleveland Clinic, 64 NCI-designated Cancer Centers, and multiple other institutions and oncology practice settings across the country.

Knowing that funding for this research is secure gives us hope. For this reason, I am requesting on behalf of the American Cancer Society Cancer Action Network that the National Institutes of Health receive a budget of \$35 billion in Fiscal Year 2011, including \$5.8 billion for the National Cancer Institute.

Thank you, Mr. Chairman, for the opportunity to testify.

Wanda Burns, RN

Wanda Burns is a registered nurse and lifelong resident of Niles, OH. Ms. Burns has worked as a nurse for 30 year. Part of her nursing career has been spent caring for patients in hospice care. In addition to her career in nursing, Ms. Burns has served two terms on the Niles Board of Health and one term on the Niles Board of Education.

Ms. Burns has also been a volunteer with the American Cancer Society's Relay for Life. She is appearing before the House Appropriations Subcommittee on Labor-HHS-Education to share the story of how her family has been impacted by cancer and the importance of sustained federal investments in cancer research.

Mr. OBEY. Thank you.

Mr. RYAN. Mr. Chairman, I would just like to say hello because Wanda is not only from my District, she is from my home town, and I want to thank her for coming up.

So thank you for your work.

Mr. OBEY. She told me a lot about you. [Laughter.]

Mr. RYAN. Let's keep that off the record, will you, Mr. Chairman? [Laughter.]

Ms. BURNS. Thank you.

Mr. OBEY. Thank you.

Next, I understand, Congressman Shimkus would like to introduce someone.

Mr. SHIMKUS. Thank you, Mr. Chairman.

It is an honor to be here, especially as I have never been in this hearing room and it is good to be here in your last years of serving, and I appreciate your service.

Thank you, Ranking Leader Rehberg also for this time.

I am here to introduce Kristin. Kristin is the widow now, wife of my former Legislative Director Ray Fitzgerald, who passed away from gastric cancer. Kristin has testified before, now I am Ranking on the Subcommittee on Health, to talk about the funding aspects of the National Cancer Institute and the issues related there.

She is a former Hill staffer, was on Education and Labor with now our Leader Boehner's staff, so she is very capable and understanding of the ways of how we work out here. She came out here on the train.

Mr. OBEY. I'm glad that somebody is. [Laughter.]

Mr. SHIMKUS. She came out on the train with Nora, Maggie and Lucy.

About half the deaths from cancer come from a deadly cancer disease, and only 17 percent of the funding goes there. And so I think in part what we had in our hearing raised that issue and talked about the proportion of where our money should go and how it should be spent. She does a much better job than I do. I am just pleased to have her still working on behalf of healthcare for all Americans, and in a legacy of my former employee and her husband, Ray Fitzgerald, who we miss dearly.

Thank you, Mr. Chairman.

Mr. OBEY. Thank you. Glad to have you.

WEDNESDAY, MAY 12, 2010.

**NATIONAL INSTITUTES OF HEALTH, NATIONAL CANCER
INSTITUTE**

WITNESS

KRISTIN W. FITZGERALD

Ms. FITZGERALD. Thank you, Congressman Shimkus, for your tireless commitment and support.

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to testify at today's hearing on the need for fiscal year 2011 funding to research gastric or stomach cancer and other gastrointestinal or GI cancers in young people.

Chairman Obey, I was also sorry to hear of your retirement, with your longstanding commitment to medical research.

I am here today not only on my own behalf, but that of my husband, Ray Fitzgerald, who died last year of gastric or stomach cancer. As you have heard, Ray was Legislative Director for Congressman John Shimkus.

Until his diagnosis in May of 2008, Ray was a healthy 36 year old man. He had no risk factors for cancer. He had never smoked, drank infrequently, and lived a healthy lifestyle. With no family history of cancer, nothing would ever have put him at a high risk of a cancer diagnosis.

Ray's cancer symptom was burping, which appeared for a period of two months before his cancer was diagnosed. When he was diagnosed, his cancer was an advanced stage four. His gastric tumor had spread throughout the lining of his stomach and progressed to his esophagus and liver.

We were told that there was no hope of a cure, but that chemotherapy could reduce the cancer for a time. That time was eight months. Let me be clear. The time between diagnosis and Ray's death was only eight months. This is not an abnormal scenario for gastric cancer. It is the second deadliest cancer worldwide. It very often presents in stage four and is always incurable at that point.

Ray, however, at 36, was 40 years younger than the average gastric cancer patient, and thus the grim prognosis impacted not just Ray, but myself and our three young daughters, Nora, Maggie and Lucy.

Members of the Subcommittee, it is my belief that Ray's diagnosis and prognosis is our worst cancer nightmare: diagnosis of a deadly cancer with very few warning symptoms at an advanced stage where cure is impossible. It is a death sentence.

After Ray died, I spent time researching how this kind of scenario can be prevented. As a former Congressional health staffer, I assumed that gastric cancer research was ongoing. However, far too little is being done to research gastric cancer and other GI cancers that have a similar deadly prognosis.

CBS News analyzed the disparity in research dollars in May of 2009. For every cancer death, the most Federal research dollars are spent on cancers of the cervix and breast. The very least funded is gastric cancer, at about \$1,100 a person.

GI cancers are some of the deadliest cancers in the United States. Four out of the five lowest five-year cancer survival rates for metastatic cancer are GI, including stomach cancer with a survival rate of only 3.4 percent.

And GI cancers are rising, particularly in young people. Last week, NCI released a study showing that a young person's likelihood of being diagnosed with gastric cancer has increased by almost 70 percent since 1977. Likewise, a recent NCI article documented a 190 percent increase in a sub-type of cancers of the stomach and esophagus in young white males like Ray.

And the situation for young people with GI cancers is particularly grim. Because of their lack of symptoms, the disease is usually in a late stage by the time a diagnosis is established. And their very age works against them as the strength and relative health of their bodies is passed on to their cancers, making them even

more aggressive than in older patients. As a result, GI cancers in young people tend to be fatal.

In my view, this is intolerable. Congress and NCI can and should do more to ensure that researchers can have access to the tools they need to prevent and diagnose these cancers before it is too late. Research is essential in order to understand the unique characteristics of the disease in younger people and develop a screening test based on molecular markers to allow for earlier detection.

In order to accomplish this research, NCI must develop a coordinated national GI cancer tissue biorepository and a research project to focus research in this area and make tumor tissue available for research purposes.

A specific research project is critical in order to obtain IRB approval to go beyond the standard of care in obtaining tumor tissue and elicit the participation of our Nation's top cancer centers.

Last year, the Labor, HHS, and Education Appropriations Report included language asking the NCI to develop a research project and biorepository to study these cancers in young people, and language for fiscal year 2011 asking NCI to report on its progress has been submitted by Congressman Jackson.

After my testimony to the Energy and Commerce Committee, work with NCI has commenced to potentially include gastric cancer in the Cancer Genome Atlas, but we need Congressional support and NCI support to ensure that these cancers can be cured.

[Written statement by Kristin W. Fitzgerald follows:]

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Kristin W. Fitzgerald

Naperville, Illinois

Labor-HHS-Education Appropriations Subcommittee

Public Witness Hearing on FY 2011 Appropriations

May 12, 2010

2:00 pm

Testimony concerning FY 2011 Funding at the Department of Health and Human Services for Programs Related to Gastric (Stomach) Cancer and other Gastrointestinal Cancers (GI) in young people at the National Cancer Institute and the National Institutes of Health

Members of the Subcommittee, I want to thank you for the opportunity to testify at today's public witness hearing on FY2011 funding for the Labor, Health and Human Services and Education Appropriations Act.

My name is Kristin Fitzgerald. As a former health staffer for Representatives John Boehner, Judy Biggert, and Harris Fawell, I know the work involved in Congressional Hearings. Thus, I particularly appreciate the opportunity to speak to the Subcommittee today on the dramatic need for funding to research gastric (stomach) cancer and other gastrointestinal (GI) cancers in young people.

I am here today not only on my own behalf, but that of my three young daughters, all of whom miss their father, my husband, Ray Fitzgerald, who died last year of gastric or stomach cancer.

Ray was also a Congressional staffer. He worked for six years as legislative director for Congressman John Shimkus of Illinois.

Until his diagnosis in May of 2008, Ray was a healthy 36 year old man. He had no risk factors for cancer. He had never smoked, drank infrequently and lived a healthy lifestyle. With a very large Irish family, there were only four unrelated incidences of cancer before him. Nothing would ever have put him at high risk of a cancer diagnosis.

Ray's cancer symptom was burping which appeared for a period of two months before his cancer was diagnosed.

When Ray was diagnosed, his cancer was an advanced stage IV. His gastric tumor had spread throughout the lining of his stomach and progressed to his esophagus and liver.

We were told that there was no hope of a cure but that chemotherapy could reduce the cancer for a time.

That time was eight months. Let me be clear, the time between diagnosis and Ray's death was only eight months.

This is not an abnormal scenario for gastric cancer, it is the second deadliest cancer worldwide. It very often presents in Stage IV, and is always incurable at that point.

Ray however, at 36, was forty years younger than the average gastric cancer patient, and thus the grim prognosis impacted not just Ray, but myself and our three young daughters, Nora (5), Maggie (3) and Lucy (1).

Members of the Subcommittee, it is my belief that Ray's diagnosis and prognosis is our worst cancer nightmare. Diagnosis of a *deadly cancer* with very few warning symptoms at an *advanced* stage where a *cure is impossible*. It is a death sentence.

And if we think it can't or won't happen to us, we are wrong. Ray was you -- or at least, your staff. And as I have learned, it could even be happening to one of us right now, and we would never know it.

After Ray died I spent time talking with Ray's doctors to see how this kind of scenario can be prevented so that more young dads and moms aren't violently stolen from their families by cancer.

As a former health staffer, I assumed that gastric cancer research was ongoing and would utilize Ray's tumor specimen and facts about his age and health status to find treatments and cures.

However, far too little is being done to research gastric cancer and other GI cancers that have a similar deadly prognosis. CBS news analyzed the disparity in research dollars in May of 2009. For every cancer death, the most federal research dollars were spent on cancer of the cervix (\$18,870) and breast (\$14,095) and on Hodgkin lymphoma (\$12,791). The least funded was gastric cancer (\$1,168), with esophageal cancer a close third at (\$1,542).ⁱ

GI cancers are some of the deadliest cancers in the U.S. with deaths attributed to the digestive system second only to those in the respiratory system. Four out of the five lowest five year cancer survival rates for metastatic cancer are GI: Pancreas 1.7%; Liver 2.8%; Esophagus 2.9% and Stomach 3.4%.ⁱⁱ These four GI cancers make up half of the eight most deadly cancers which together account for almost half of the United States' cancer deaths.ⁱⁱⁱ Yet, research to treat and cure these cancers accounts for a vastly disproportionate percentage of NCI's funding.
Attachment 1

And, GI cancers are rising, particularly in young people. Just last week, the National Cancer Institute (NCI) released a study based on surveillance tracking of gastric cancer. Gastric cancer was declining in every age range except age 25-39. There, one's likelihood of being diagnosed with gastric cancer has increased dramatically by almost 70 percent since 1977.^{iv}

Likewise, a recent NCI article documented the rise in gastroesophageal cancers of the stomach and esophagus. The article compared the incidence rates in two four year periods, 1975-1979 and 2000-2004. Overall there was a 44 percent increase in these cancers. Within gastroesophageal cancers there was an explosion of a particular type, adenocarcinoma, the type Ray had. The increase in adenocarcinoma was 465 percent, with an 190 percent increase in young white males.^v

And the situation for young people with GI cancers is particularly grim. Because GI cancers are considered to be diseases of middle or advanced age, the diagnosis of GI cancers in people under 40 is often delayed. As a result, the disease is usually in an advanced stage with a poor prognosis by the time the diagnosis is established. And their very age works against them as the strength and relative health of their bodies is passed on to their cancers making them even more aggressive than in older patients. As a result of the delay in diagnosis and the more aggressive phenotype of cancers in young people, GI cancers in young people tend to be fatal.

Yet, unlike other deadly cancers, gastric cancer and many other GI cancers do not have a national clinical registry and tissue bank, to utilize tumor tissue and clinical records for research purposes.

In my view, this is intolerable. Congress and NCI can and should do more to ensure that researchers can have access to the tools they need to prevent and diagnose these cancers before it is too late.

Though these cancers are growing, they are poor candidates for wide-scale screening programs due to the smaller population of people impacted and the invasive nature of screening available.

More research is *essential* in order to understand the unique characteristics of the disease in younger people and develop a *screening test based on molecular markers to allow for earlier detection*.

In order to accomplish this research, NCI must develop a coordinated national GI cancer tissue biorepository, and accompanying research project to focus research in this area and make tumor tissue available for research purposes. *A specific research project is extremely important* as difficulties in obtaining tumor tissue, make a specific research project important in order to obtain Institutional Review Board (IRB) approval to go beyond the standard of care in obtaining tumor tissue.

Last year the Labor, HHS, and Education Appropriations Report included language asking the NCI to develop a research project and accompanying tissue repository to study GI cancers in young people.

Language for FY 2011 asking NCI to report on its progress to the Subcommittee has been submitted by Congressman Jesse Jackson, Jr.

After my testimony to the House Energy and Commerce Health Subcommittee on the increase of these deadly cancers in young people, work with NCI has commenced to develop alternative

appropriations language for FY2011 to include gastric cancer in the Cancer Genome Atlas and set forth projects to study gastric cancer, but research projects have not yet begun.

Congress must act to ensure that these cancers can be detected and cured so that more lives are not lost.

Ray was a wonderful man and the legacy of his *spirit* will live on always. However, it is my belief that Congress should fund a research project, tissue bank and registry so that the *physical legacy* of patients like Ray can *live on forever, giving eternal gifts to researchers and scientists throughout the world.*

Members of the Subcommittee thank you for your time and consideration. I am happy to answer any questions.

ⁱ Data compiled and reported by CBS Evening News, May 27, 2009.

ⁱⁱ American Cancer Society. Cancer Facts & Figures 2008. Atlanta: American Cancer Society; 2008.

ⁱⁱⁱ Deadly Cancer Coalition. The Deadliest Cancers. Washington, D.C.: 2010.

^{iv} "Age-Specific Trends in Incidence of Noncardia Gastric Cancer in US Adults," William F. Anderson, MD; M. Constanza Camargo, MSc; Joseph F. Fraumeni Jr, MD; Pelayo Correa, MD; Philip S. Rosenberg, PhD; Charles S. Rabkin, MD, Journal of the American Medical Association, May 5, 2010; 303(17):1723-1728.

^v "Incidence of Adenocarcinoma of the Esophagus Among White Americans by Sex, Stage, and Age," Linda Morris Brown, Susan S. Devesa, Wong-Ho Chow, Journal of the National Cancer Institute 2008;100: 1184 – 1187.

KRISTIN WOLGEMUTH FITZGERALD**EXPERIENCE****FITZGERALD CONSULTING***Principal, January 2004 through November 2008*

Founded successful consulting business, applying extensive health policy and government affairs experience to advise clients on health policy and strategy.

HOUSE OF REPRESENTATIVES COMMITTEE ON EDUCATION AND THE WORKFORCE*Professional Staff June 2001 through January 2004*

Responsible for health care and pension policy within the jurisdiction of the Education and Workforce Committee. Wrote and analyzed legislation; acted as Committee Counsel for hearings and markups of legislation; prepared speeches, memos and detailed analysis of legislation for Members and staff; and represented the Chairman and Subcommittee Chairman in meetings with House Leadership, outside groups, and other interested parties.

HEALTHCARE LEADERSHIP COUNCIL*Assistant V.P. for Government Affairs/Grassroots, Oct 2000 through June 2001*

In addition to responsibilities as Director of Government Affairs/Grassroots, served as a part of the Executive Staff. Assisted in development of yearly planning for the organization, and strategy for legislative and policy goals.

Director of Government Affairs/Grassroots, July 1999 through Oct 2000

Directed all grassroots education and advocacy efforts to implement HLC legislative and policy positions. Managed seven grassroots field consultants and two person D.C. support team that implemented all HLC grassroots initiatives.

CONGRESSWOMAN JUDY BIGGERT (R-IL)*Legislative Director, January 1999 through July 1999**Washington, D.C.*

Served as principal legislative advisor to Congresswoman Biggert for her committees of jurisdiction, the House Committees on Banking and Government Reform, along with health, education, and labor issues. Hired, trained and supervised all legislative staff.

CONGRESSMAN HARRIS W. FAWELL (R-IL)*Chief of Staff, May 1998 through January 1999*

Responsible for all legislative, administrative and communications management for the Washington staff of eight. Served as chief legislative advisor, worked regularly with committee and House Republican leadership staff, Illinois Congressional Delegation, and outside interest groups. Advised the Congressman on health, labor, pension and education issues.

Legislative Director, November 1996 through May 1998

Directed all legislative activities, constituent casework and correspondence for the Washington Office. Supervised legislative staff of five. Researched and implemented legislative initiatives in education and environmental policy.

EDUCATION

TAYLOR UNIVERSITY, UPLAND INDIANA

Bachelor of Science, Political Science 1993, GPA 3.6

Awarded Taylor Leadership Scholarship

VOLUNTEER WORK

Naperville Township Republican Organization, Precinct Committeeman, March 2006-present

Naperville Park District, Assistant Soccer Coach, September 2009-present

St. Raphael Catholic Church, Sunday School Teacher, September 2007-present

Mr. OBEY. Thank you very much. We are sorry for your loss.
Next, E. Clarke Ross, Friends of NCBDDD.

WEDNESDAY, MAY 12, 2010.

**CENTERS FOR DISEASE CONTROL, NATIONAL CENTER
FOR BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES**

WITNESS

**E. CLARKE ROSS, CHAIR, FRIENDS OF THE NATIONAL CENTER FOR
BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES**

Mr. ROSS. Thank you, Mr. Chairman. I am representing the Friends of the National Center on Birth Defects and Developmental Disabilities at CDC. According to the National Council on Disability, there are 54 million Americans with disabilities, and NCBDDD is the disabilities center at CDC.

I have had the privilege of working for 40 years with five different national disability organizations and I brought a photo of you that I was at with the leadership of United Cerebral Palsy of Wisconsin from the late 1970s or the early 1980s.

Mr. OBEY. That guy is an imposter. [Laughter.]

Mr. ROSS. People recognize you. People recognize you.

We are asking for a \$20,000,000 increase in the appropriation for NCBDDD. That is a 14-percent increase over the \$143,000,000 level of the current level and NCBDDD would do five things with this \$20,000,000. One is to enhance wellness and prevention initiatives for people with disabilities. This is a big priority of the First Lady, obesity. The new CDC Administrator's big priority is anti-smoking, obesity, infectious diseases.

I am the father of a 19-year-old son with high-functioning autism and non-attentive ADHD, significant anxiety and learning disabilities. He is 19. He is right out of high school. And what does he do left to his own druthers? He sits in his apartment and watches TV and does Game Boy kinds of things.

So this population is very socially isolated. And unless we have aggressive NCBDDD programs that deal with things like social isolation in this population, what are guys like my son going to do? They are going to eat. Fortunately, he does not drink or smoke or do drugs, but what he is going to do when he is socially isolated by himself is use behaviors that are not very positive and helpful.

So we would use some of this \$20,000,000 to deal with health and wellness programs like the First Lady and the CDC Administrator desire.

We also need to do a lot in the health disparity area. The disability population itself is highly under-served compared to the population at large. Many of the witnesses are consumers and family members. A high priority of NCBDDD is to educate family members and consumers about all of these disabilities, how to deal with the disabilities, how to plan your life around the disabilities. That is a third area.

The fourth area is a big need. We have a good special education law in this Country. We have 6.5 million kids in special education. They come out of high school. We as a society are not really dealing

with the transition from high school to employment or college, and we need a lot of planned supportive activities to help young adults.

And this is very consistent with the whole employment initiative. We need to help people get employed. We need to support them in employment, and NCBDDD can do that with an increase in appropriations.

And last, NCBDDD does do global health work like folic acid distribution around the Country to prevent birth defects.

So \$20,000,000, these are the five things the Friends would like to see money used for.

[Written statement by E. Clarke Ross, D.P.A., follows:]



Friends of NCBDDD

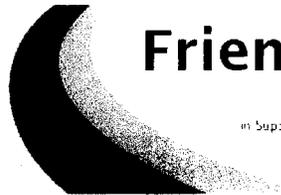
in Support of the National Center on Birth Defects and Developmental Disabilities

Testimony
Before the Subcommittee on Labor, Health and Human Services, Education, and
Related Agencies
Committee on Appropriations
United States House of Representatives

Statement of
E. Clarke Ross, D.P.A., CEO
CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder
Landover, MD 20785
2010-2011 Chair, Friends of NCBDDD at CDC
Public witness hearing on Wednesday, May 12, 2010 2:00 PM to 4:30 PM

Friends of NCBDDD Request \$20 Million Increase to NCBDDD's FY 2011 Base
Budget

The Friends is a coalition of approximately 100 national organizations. The Friends executive committee is composed of American Academy of Pediatrics, American Association on Health and Disability, Association of University Centers on Disabilities, CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder, Christopher and Dana Reeve Foundation, Easter Seals, March of Dimes, National Alliance for Thrombosis and Thrombophilia, National Birth Defects Prevention Network, and National Tourette Syndrome Association.



Friends of NCBDDD

in Support of the National Center on Birth Defects and Developmental Disabilities

Statement Summary -Friends of NCBDDD – CDC National Center on Birth Defects and Developmental Disabilities – Clarke Ross, 2010-2011 Chair, May 12, 2010

The Friends of NCBDDD, a coalition of approximately 100 organizations, support the extraordinary work of the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities (NCBDDD). I have been personally involved with the Friends since its inception in 2001.

Mr. Chairman: I have spent 40 years working with 5 national mental health and disability organizations here in the nation's capital. I am pleased to share with you a photograph I have with you from the late 1970s or early 1980s with United Cerebral Palsy of Wisconsin leaders. On behalf of the Friends, please accept our deepest appreciation and respect for the decades of leadership you have demonstrated to persons with disabilities. We are sad that you are retiring.

I am the father of a 19 year old son with high functioning autism, inattentive ADHD, significant anxiety, and learning challenges. As a father of Andrew, please accept my personal appreciation for your work.

The Friends recommend that Congress provide at least a \$20 million or 14% increase over the FY10 level of \$143.539 million for NCBDDD in FY 2011. I am pleased to submit our view on what can be accomplished with increased federal funding for NCBDDD.

We ask the Congress to appropriate an additional \$20 million for NCBDDD as a sound public health investment that will:

1. Enhance wellness and prevention initiatives for children and adults with disabilities
2. Reduce health disparities between children and adults with disabilities and the non-disabled population
3. Provide educational materials to improve medical awareness by consumers and their families
4. Enable CDC to better facilitate transition from childhood to adulthood for people with disabilities
5. Strengthen NCBDDD's global health improvement work

The NCBDDD serves many highly vulnerable populations with pressing public health problems at a time of economic stress. The number of people living with birth defects, developmental disabilities, blood disorders or acquired disabilities is rising and expected to increase over the next decade. With at least 54 million Americans currently experiencing a physical, cognitive, or sensory limitation, this is a serious health issue.

Established in 2001, NCBDDD's mission is to promote the health of babies, children and adults and enhance the potential for full, productive living. We submit a two page fact sheet of recent NCBDDD accomplishments.

The President and Congressional leaders have announced the need to continue to increase jobs in our society. My son Andrew is struggling a year out of high school. Many of the NCBDDD initiatives will increase or maintain employment. My employer – CHADD – is looking for resources to enhance our support to individuals with ADHD and co-occurring disorders in their effort to secure employment. Thank you. Our statement has been submitted. We welcome questions.

NCBDDD is CDC's lead National Center on disability and serves many highly vulnerable populations with pressing public health problems. The Center includes three divisions: the Division on Birth Defects and Developmental Disabilities; the Division on Human Development and Disability; and the Division on Blood Disorders. The Friends appreciates the subcommittee's support of the NCBDDD over the years and, while one of the smaller national Centers at CDC, the Center achieved a number of significant accomplishments during the past year, which can be found in the factsheet submitted as part of my testimony.

The Friends of NCBDDD (Friends) is a coalition of over 100 organizations that work together to enhance the mission and activities of NCBDDD. The "Friends" officially formed in 2002 and grew out of efforts to pass the Children's Health Act which authorized the NCBDDD. The Friends is dedicated to supporting the broad base work of the NCBDDD by disseminating information and educating all about the work of the Center. I have been personally involved with the Friends since its inception and its growth is a testament to the importance of NCBDDD's work. I am pleased to submit our view on what can be accomplished with increased federal funding for NCBDDD and respectfully recommend Congress support a \$20 million increase to NCBDDD's FY 2011 budget, which is a 14% increase over the FY 2010 level of \$143.539 million.

While these achievements are significant, the challenges facing NCBDDD are daunting given that at least 54 million Americans currently experience a disability and current projections indicate that the number of people living with birth defects, developmental disabilities and blood disorders will continue to increase over the next decade. Although the NCBDDD is dedicated to alleviating the health issues of these vulnerable populations, its budget has remained relatively flat since 2005. A \$20 million increase in NCBDDD's base funding is a sound public health investment that would be responsive to the anticipated trends in disability prevalence and would provide NCBDDD a degree of flexibility as it seeks to meet the needs of these vulnerable populations over the next decade. This increase could be used to support a variety of critical disability and health programs focused on:

- Enhancing Wellness and Prevention for children and adults with disabilities
- Reducing Health Disparities between children and adults with disabilities and the non-disabled population
- Providing Educational Materials to Consumers and their Families to Improve Medical Awareness
- Facilitating the Transition from Childhood to Adulthood for People with Disabilities
- Supporting Improved Global Health

Enhance Wellness and Prevention

NCBDDD is faced with the dual challenge researching why birth defects occur and how to prevent them as well as developing programs to enhance the wellness of those suffering from disabilities. With more than 4 million births annually in the United States, every woman needs accurate and clear health information about how to care for herself and if she is pregnant or planning to become pregnant she has additional

informational needs to assure the health of her unborn baby. Increased support is needed for CDC to continue their important research to learn more about what women can do even before they become pregnant to prevent birth defects and other developmental problems.

Another good example is NCBDDD's Early Hearing Detection and Intervention (EHDI) program. Identifying infants with hearing loss is known to be cost effective and early identification can improve the delivery and timeliness of healthcare services to infants and children with hearing loss and their families. The EHDI program currently screens 94% of the newborns in the United States but more can be done. Building on its existing state-based program, NCBDDD's EHDI program could be enhanced to ensure that its tracking and surveillance systems were taking advantage of existing data in electronic health records (EHR) to improve national data reporting and coding standards. If fully supported, it is possible that this nation could achieve \$2.6 billion in educational savings alone by reducing intervention costs through enhanced early detection.

Likewise, there is currently no comprehensive system for ensuring long term follow-up with children screened for potentially disabling or life-threatening conditions. NCBDDD could expand on its existing state-based relationships to develop systems for birth defects and developmental disabilities surveillance and research to identify interventions and track changes over time. Additional funding could help build state public health capacity for long-term follow-up and increase availability of data on conditions.

In a similar fashion, the mortality associated with Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE) is more than the combined total number of deaths from breast cancer, AIDS, and motor vehicles crashes. Pulmonary Embolism alone is the leading cause of preventable hospital deaths and maternal mortality in the United States. The estimated annual healthcare costs associated with DVT/PE range from \$2 to \$10 billion. While the burden and costs are high, there is a lack of consensus within the healthcare community on prevention, diagnosis, and management of DVT/PE. Additional funding could help establish a single set of standardized, evidence-based guidelines for early recognition, treatment and management of DVT/PE and increase provider, patient, and public awareness of DVT/PE through education materials.

Reduce Health Disparities

It is critical that NCBDDD be supported in their efforts to address the health disparities associated with people with disabilities (PWD). We know that approximately 54 million Americans live with a disability and that the burden of preventable health problems is higher with PWDs than people without disabilities. For example, people with disabilities suffer from increased smoking rates (62% of this population is more likely to smoke) and higher obesity rates (57% of this population has higher rates of obesity than non-disabled people). NCBDDD is well positioned to address these issues through existing programs that could be augmented with additional funding. An increase in its base funding could be used to expand existing state-based disability and health programs from 16 to 34 U.S. states and territories and reduce the impact of health disparities for PWDs by focusing on chronic disease prevention in these populations.

Additionally, there are certain disabling conditions that disproportionately impact minority populations in this country. For instance, the majority of the 100,000 people in the U.S. suffering from hemoglobinopathies like sickle cell disease (SCD) or thalassemia are African-American. Modest efforts to address the burden associated with sickle cell disease and thalassemia have already begun through an innovative collaboration between NCBDDD and NIH's National Heart, Lung and Blood Institute. In 2010, CDC and NHLBI partnered to establish the Registry and Surveillance System for Hemoglobinopathies (RuSH) in 6 states. Increased funding could also help expand the Registry and Surveillance System for Hemoglobinopathies (RuSH) from six to twelve states and permit CDC to capture 66% of the African-America population afflicted with SCD in the RuSH system.

Providing Educational Materials to Consumers and their Families to Improve Medical Awareness

The rare nature of many of the conditions falling within NCBDDD's areas of responsibility present the Center with the challenge of educating individuals, families, caregivers, providers, as well as the general public about these conditions. It is critical that NCBDDD have the resources necessary to educate them about these conditions in an effort to prevent or mitigate their impact and help people live full and productive lives. At the same time, these efforts can help avoid unnecessary and avoidable healthcare expenditures for the individuals, their families or caregivers, and society as a whole. NCBDDD has initiated efforts to address these issues but limited resources prevent the Center from maximizing their impact.

Currently in the United States, 13% of children have a developmental disability, which includes attention deficit/hyperactivity disorder, autism spectrum disorders, cerebral palsy, hearing loss, intellectual disabilities, vision loss, and others. Yet, less than 50% of developmental delays are identified before starting school, missing critical opportunities to intervene early and prevent the onset of negative health outcomes such as chronic diseases, smoking, drug use, and depression. This relatively late age of diagnosis is a reminder of how important it is to be aware of milestones that mark a child's development and to act early if a delay is suspected. Additional funding could be used to expand NCBDDD's Learn the Signs, Act Early Campaign, which provides families, educators, and healthcare providers with the training and materials they need to identify delays early and coordinate critical services at a time that maximize the impact on child's development.

Facilitating the Transition from Childhood to Adulthood for People with Disabilities

As medicine and science advance, people suffering from birth defects and disabilities are living longer and potentially, more productive lives. However, while scientific advancements have been rapid, the healthcare system often struggles to keep pace with the service needs of the PWD population. It is critical that we begin to dedicate resources to support the transition from childhood to adulthood for people with

disabilities. Again, NCBDDD has initiated efforts to address these issues but limited resources prevent the Center from maximizing their impact.

For instance, my organization established the National Resource Center on Attention Deficit/Hyperactivity Disorder (ADHD) which is the only national clearinghouse dedicated to sharing evidence-based information about identification, support, referral, and treatment for ADHD. Through support from NCBDDD, the Resource Center fields more than 12,000 inquiries and 1.1 million hits on its website each year; thereby providing important health and life information to children and adults with ADHD, as well as their families, caregivers, and other vital stakeholders.

In addition, NCBDDD has developed a web-based resource for parents and health professionals to guide the care and monitoring of children with Spina bifida across the life course. The resource contains a range of topics including health, self care, personal relationships, employment, income, and is expected to be launched late this year. Additional funding support would provide an opportunity to expand both its impact and reach.

Finally, thanks to recent medical advances, the diagnosis of a congenital heart defects (CHD) is no longer a death sentence and 90% of children with CHD survive to adulthood; resulting in an estimated one million adults currently living with CHD. These adults have significantly higher rates of health care utilization than their age-matched peers. With the potential rapid rise in the number of adults with CHD and their unknown health care needs, the corresponding increase in health care services could overwhelm the existing system. You and your colleagues in the House and Senate recognized the importance of this issue when you passed the Congenital Heart Futures Act as part of health reform. While this law gives CDC authority to act no funds were appropriated to fund these activities. An increase in funding at NCBDDD could be used to implement this important piece of legislation and help CDC better understand the disease burden and long-term outcomes in this population including the evaluation of evidence-based treatments. This expanded knowledge then can ensure individuals with CHD have the necessary information to lead healthier and productive lives in any life stage.

Supporting Improved Global Health

As alluded to throughout this testimony, this country has achieved some remarkable advances in birth defects prevention over the last 20-30 years. A noteworthy example is the prevention of neural tube defects (NTD) since mandatory flour fortification began in the United States in 1998. The Friends believe that NCBDDD is uniquely positioned to roll some of these advances out to the global community and have a significant impact on the health of children throughout the world. For instance, spina bifida and anencephaly, the most common forms of NTD, occur in an estimated 300,000 newborns worldwide. Data indicate that at least half the cases of NTDs could be prevented if women consumed sufficient amount of folic acid prior to and during early pregnancy. NCBDDD, in conjunction with its CDC partners and ministries of health, could implement a global folic acid fortification program in countries with the highest NTD burden, as a strategy for achieving similar results in other countries as those seen in our own.

In conclusion, the Friends of NCBDDD support NCDDD's mission of promoting the health of babies, children and adults and enhancing the potential for full, productive living for those with disabilities. Expanding NCBDDD's FY 2011 budget base by \$20 million will further enable it to have greater flexibility to expand upon the surveillance and research that are so vital to ensuring healthy birth outcomes, follow up and treatment for children with disabilities and ensure a smooth transition from childhood to adulthood. The Friends of NCBDDD therefore recommends that Congress provide a \$20 million increase to NCBDDD's FY 2011 budget. We submit a two page fact sheet of recent NCBDDD accomplishments to further support the far reaching impact of these programs.

E. Clarke Ross, CEO of CHADD

Clarke Ross currently serves as the Chief Executive Officer of CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder.

Clarke is the 2010-2011 Chair of the Centers for Disease Control and Prevention (CDC) “Friends of NCBDDD” (National Center on Birth Defects and Developmental Disabilities).

Clarke has worked for almost 40 years with five national mental health and disability organizations. His work history includes Deputy Executive Director for Public Policy, NAMI – National Alliance on Mental Illness; Executive Director, American Managed Behavioral Healthcare Association (AMBHA); Assistant Executive Director for Federal Relations and then Deputy Executive Director, National Association of State Mental Health Program Directors (NASMHPD); and Director of Governmental Activities, UCPA – United Cerebral Palsy Associations (UCPA).

He holds two masters degrees – one in history and political science from the University of Maryland, the other in health services administration from the George Washington University. He completed his undergraduate studies in history and political science at the University of Maryland. Awarded a State of Maryland Maternal and Child Health Fellowship, Clarke completed a health administration residency at Johns Hopkins University Medical Institutions. His doctorate is in public administration (D.P.A.) from The George Washington University, class of 1981. A former VISTA volunteer, he has taught graduate classes for Central Michigan University since 1983 and also for both the University of Maryland and Southeastern University. From 1984-1986, Clarke worked as an Assistant Professor of Public Administration for Troy State University – European Region, headquartered in Weisbaden, Germany. Dr. Ross is a Fellow of the American College of Mental Health Administration (ACMHA)

Clarke has authored 13 book chapters and 33 journal articles, mostly on the organization and financing of the public mental health system and political interest group behavior. Dr. Ross is the editor of a textbook on managed behavioral health care, Managed Behavioral Healthcare Handbook (Aspen Publishers, 2001). Dr. Ross is the author of the chapter on managed care in Mental Health, United States, 2000, a biennial publication of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

He is the father of a 19-year-old son with special challenges.

CHADD, 8181 Professional Place, Suite 150, Landover, Maryland 20785.
301-306-7070, extension 111 clarke_ross@chadd.org January 2010

Mr. OBEY. All right. Thanks again.
Next, Vicki Modell, Jeffrey Modell Foundation.

WEDNESDAY, MAY 12, 2010.

**NATIONAL INSTITUTES OF HEALTH, OFFICE OF PUBLIC
HEALTH GENOMICS**

WITNESS

VICKI MODELL, CO-FOUNDER, JEFFREY MODELL FOUNDATION

Ms. MODELL. Mr. Chairman and Members of the Committee, thank you so much for this extraordinary opportunity to testify today.

My husband and I created the Jeffrey Modell Foundation in memory of our son Jeffrey, who died at the age of 15 after a lifelong battle with primary immunodeficiency. PI diseases afflict more than 1 million Americans, but most of them go undiagnosed.

Over the past 12 years that we are coming to Washington, you have given us the opportunity to build a strong partnership with Congress, CDC, NIH, as well as industry and private donors. Now, I would like to tell you where we are, where we are going with your continued support, and some changes that are needed in the President's budget request that will allow us to continue to help our patients and save lives.

This Committee provided the funding for physician education and public awareness programs. Working with CDC, we started the campaign five years ago and our public service ads have generated more than \$130,000,000 in donated media. It has enabled us to generate additional funding from the private sector, and we are very proud to report that every \$1 of Federal funds provided has been leveraged into more than \$10 for our program.

I am delighted to report that this initiative is having exactly the impact that we all had hoped for. Physicians at our 79 Jeffrey Modell Centers in the U.S. report a doubling every year in the number of patients diagnosed and treated. And severe infections, hospitalizations, school and workdays missed were reduced by an average of 70 percent. This generates a savings to the healthcare system of more than \$80,000 per patient per year.

Since the NIH reports that there are 500,000 Americans with PI who are undiagnosed, the wasted cost to our healthcare system is \$40,000,000,000 annually. All of this has been published in a peer-reviewed journal.

This program is successful, but here is the problem. The President's budget for fiscal year 2011 reduces funding for the Office of Public Health Genomics and eliminates the line items created by this Committee to fund the education and awareness programs. While CDC has indicated its support, the only guarantee that it will go forward is if this Committee supports that and acts.

For this reason, we are requesting that when you assemble the Chairman's mark for the bill, you return this account to the current status, as was found in the fiscal year 2010 bill. The program is working and it has earned your continued support.

An additional success story for this Committee and by this Committee, I may say, is the newborn screening program that was funded and piloted in Wisconsin and Massachusetts by CDC and our Foundation. Today, every baby born in those two States is being screened for this life-threatening condition, and potentially cured. The cost of the screening is less than \$5 per baby. Now, that is priceless.

That is why this past January the Secretary's Advisory Committee voted unanimously to add SCID testing to the national core panel.

I received a note from a mother in Edgar, Wisconsin, not far from you, whose baby was screened, transplanted, and has been completely cured. The impact of this Committee is extremely well expressed in her note: "We are so blessed to have our beautiful baby Dawson. Every day I feel we are the luckiest family in the world. I always think about the time we testified in D.C. and we sat next to the parents from Oregon who lost their baby Liam to SCID. That could have been us. This September will be Dawson's two-year anniversary of his transplant. We cannot imagine life without him."

Well, tomorrow 11,000 babies will be born in this Country, but only 300 to 400 of them will be born in States that currently screen for SCID. They will be the lucky ones. They will have a chance of life. If every State would screen for SCID, we could actually wipe out this deadly disease. What a great legacy for this Committee.

So Fred and I accept the reality that science and discovery did not come in time to save Jeffrey, but we are dedicated and committed to work with you so that all the Jeffreys in the future will have a healthy life. This is our hope. It is our dream. Let's go forward on this journey together starting today.

Thank you and thank you for your service for so many years.

[Written statement by Vicki Modell follows:]

PUBLIC WITNESS TESTIMONY
HOUSE APPROPRIATIONS SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION

VICKI MODELL

CO-FOUNDER

JEFFREY MODELL FOUNDATION

NEW YORK, NEW YORK

WEDNESDAY, MAY 12, 2010
2:00 PM – 4:30 PM

PRIMARY IMMUNODEFICIENCY

Mrs. Modell will be discussing both the education and awareness program and the newborn screening activities related to Primary Immunodeficiencies in the Centers for Disease Control and Prevention (CDC) in the Department of Health and Human Services.





Testimony of Vicki Modell for the Jeffrey Modell Foundation
House Appropriations Subcommittee on
Labor, Health and Human Services and Education
May 12, 2010

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to present this testimony to the Subcommittee. My husband Fred and I created the Jeffrey Modell Foundation in 1987 in memory of our son, Jeffrey, who died at the age of 15 as a result of a life long battle against one of the estimated 160 primary immunodeficiency (PI) diseases.

The Jeffrey Modell Foundation is an international organization with its headquarters in New York City. In the 24 years since we established it, the Foundation has grown into the premier advocacy and service organization on behalf of people afflicted with primary immunodeficiency diseases. As a demonstration of the extent to which the JMF leads in the field, please consider the following:

- The Foundation has created Jeffrey Modell Research and Diagnostic Centers at 72 academic and teaching hospitals from coast to coast in the United States and throughout the world. They are located on every continent. In addition, we are affiliated with more than 415 referring physicians at 171 academic medical centers in 59 countries and 169 cities, again located on every continent throughout the world.
- The Foundation conducts a National Physician Education and Public Awareness Campaign, currently funded with approximately \$3.1 million appropriated by this subcommittee to the Centers for Disease Control and Prevention (CDC) and awarded by competitive contract to the Foundation. **To date, the Foundation has leveraged the federal money to generate in excess of \$125 million** in donated media with hundreds of thousands of placements on television, radio, print, and other public media, as well as a 30-minute program produced for PBS. The Campaign has also included physician symposia, conducted for CME credits in locations throughout the country. It has included mailings to physicians in a variety of specialist and primary care fields, including pediatrics and several pediatric specialties, family practice, and internal medicine, as well as school nurses, clinical and registered nurses and daycare centers.
- In addition, the Jeffrey Modell Foundation has been the leader in advancing newborn screening for some of the most severe forms of PI. Working with CDC, NIH, UCSF and private industry, we helped fund the development of a newborn screening test that was pilot tested in Wisconsin. The results were so successful that Wisconsin and

Massachusetts have now implemented population-based screening of every baby born in their states. Then, in January of this year, we were successful in having the Secretary's Advisory Committee for Children with Heritable Disorders add this test to the core panel of 29 newborn screening tests recommended for the states to utilize. It is the first test to be added since the core panel was created in 2005. The test is already saving lives and we know that as more states adopt it, many more will be saved.

First and foremost, Mr. Chairman, we want to thank you and all the members of this subcommittee on both a personal and a professional level. Personal because whenever we come to Washington, whether it is to testify here before the committee or to meet with the members of the subcommittee individually in their offices, every Member of Congress and every member of your staffs are unfailingly polite, courteous, interested and caring. The warm and understanding response that we receive makes this a labor of love for us.

And, professional because over the twelve years that we have been coming to Washington, we have been given the opportunity to build a partnership with the Congress, the Centers for Disease Control and Prevention, the National Institutes of Health, as well as with our own supporters in the private sector, including industry and other concerned donors. We believe that we have maximized the benefits for patients from the support that this subcommittee has afforded us. I would like to take a few minutes to discuss where we are, where we are going with your continued support, and some changes that are needed in the President's budget request to help us help patients.

PI Education and Awareness Program

This subcommittee is currently providing CDC with **\$3.1 million** for physician education and public awareness of immunodeficiencies for FY10. This is part of an overall budget of **\$12.3 million** for the Office of Public Health Genomics, which uses the remaining \$9.2 million for its operations.

Since the Campaign's inception, it has generated more than \$125 million in donated media, including television and radio spots, magazine ads, billboards, airport signs and other print media. It has also enabled us to generate additional funding from the private sector – both individuals and the pharmaceutical industry. To this point, **every \$1 of federal funds provided by the subcommittee to this program has been leveraged into more than \$10 for this education and awareness program.**

Most importantly, Mr. Chairman, I am delighted to report to you that the program that this subcommittee has funded is having exactly the impact that all of us hoped it would when it was created. Allow me to give you some specifics.

Surveying the physicians at the Jeffrey Modell Centers Referral Network we have learned that **the number of patients referred, diagnosed and treated has doubled every year** since the program's inception. The negative health outcomes of undiagnosed cases – **infections, hospital and physician visits, and similar costs – decreased an average of 70 percent** for diagnosed patients.

But, it is fair of this subcommittee to ask “so what?” What difference does it make to the health of these patients if they are now in treatment? What is the real impact in a real world sense on the patients that are found?

The economic impact of PI diagnosis has been carefully assessed comparing the costs of treatment before diagnosis and after. In round numbers what we learned was that the average annual cost of health care for an undiagnosed patient is \$103,000 per year. The same costs for the same patients in the year after diagnosis are \$23,000. **The gross annual savings to the health care system is \$80,000 per patient.**

Mr. Chairman, this program is working and we are delighted. But this is where the problem comes along. The President’s budget for FY11 reduces funding for the Office of Public Health Genomics from \$12.3 million to \$11.7 million. Further it eliminates the line item created by this subcommittee to fund the education and awareness program. While CDC has indicated its support for continuing the program, the only guarantee that will happen is if you act.

For this reason, we are asking that you take three modest steps as you are assembling the Chairman’s Mark for the bill:

- **First, restore the total line item for the Office of Public Health Genomics to its FY10 level of \$12,308,000.**
- **Second, break that money out into two separate lines, as its now – \$9,201,000 for the Office and \$3,107,000 for PI Education and Awareness.**
- **Third, so that there is no misunderstanding, include a paragraph of Committee Report language that says:**

The Committee believes that the education and awareness program for primary immunodeficiencies has been a model of public-private cooperation and therefore has restored the current structure for the Office of Public Health Genomics budget. The program’s success in leveraging public money for private investment has resulted in a huge return on the federal dollar, led to reduced health disparities, and will save lives as the program directs greater attention to newborn screening.

Newborn Screening Program

As described above, early diagnosis is critical to the health of patients and to saving the health care system money. And, there are few better examples of early diagnosis than newborn screening. The JMF has worked long and hard to support the development of a newborn screening program for some of the most severe and deadly forms of PI.

Early detection of these diseases through newborn screening is critical because bone marrow transplants cure over 98 percent of infants who have the procedure before developing any serious

infections. The treatment costs less than \$10,000. However, if an infant receives a transplant after developing severe infections, the success rate is only between 60 and 70 percent; the costs associated with the treatment of these infants can be as high as \$1 million over their lifetime.

As described above, the Secretary's Advisory Committee on Children with Heritable Disorders has recommended to the Secretary that this test be added to the core panel that forms the basis of newborn screening in states throughout the nation. It is the first time the list has ever been amended since it was created five years ago. The Jeffrey Modell Foundation is proud to have played a role in this advancement for babies and we are urging the Secretary to accept the recommendation promptly.

Once she has done so, newborn screening officials in numerous states have advised us that they will move forward with including this test in their states. At that time, the Foundation is committed to moving forward with the production of educational materials for state labs and families that will provide the information they need to consider the results of the test their baby is having. **The funds for the education and awareness program are critical for making the most of this important improvement in public health.**

Conclusion

With the support the Jeffrey Modell Foundation has received from this subcommittee over the years, we have been able to increase the public's awareness of PI and most importantly improve and save lives. We are grateful for your past and continued support. While we understand that the subcommittee must make difficult decisions in this fiscal environment, please remember that the Foundation has successfully leveraged federal dollars to expand the reach of all of our activities. Frankly, the collaboration between the federal government and the Jeffrey Modell Foundation has been a model for successful public-private collaborations. The impact of every federal dollar spent on the education and awareness campaign and on newborn screening has been exponentially increased by our commitment to bring the Foundation's resources to bear.

We ask again that you restore the funding to FY10 levels; break out PI Education and Awareness into a separate line item; and include the report language provided to assure that this program maximizes its impact.

Mr. Chairman, again, we are delighted to have the opportunity to present to the subcommittee and stand ready to work with you.



Vicki Modell

Co-Founder, Jeffrey Modell Foundation



In 1987, Vicki Modell, with her husband Fred established the Jeffrey Modell Foundation in memory of their son Jeffrey, who died at the age of fifteen from complications of Primary Immunodeficiency – a genetic condition that is chronic, serious and often fatal. JMF is a global a 501 (c) (3) nonprofit organization committed to early and precise diagnosis, meaningful treatments, and ultimately, cures through clinical and basic research, physician education, patient support, advocacy and public awareness. The Foundation has developed a global Network of more than 72 Jeffrey Modell Diagnostic and Research Centers worldwide...consisting of 415 expert physicians at 172 referral centers in 169 cities in 53 countries on 6 continents....and continues to expand globally.

The Jeffrey Modell Foundation conducts national and international scientific symposia including the World Health Organization/IUIS Expert Meeting on Primary Immunodeficiencies. Over the years, Jeffrey's Foundation has organized more than 40 physician and patient conferences worldwide.

The Jeffrey Modell Foundation has funded more than 25 post-doctoral fellowships and recently initiated the first population based newborn screening program for SCID. The Modells established and funded the Jeffrey Modell Immunology Center, a newly constructed building on the Harvard Medical School Campus. Currently, there are four Jeffrey Modell Endowed Chairs in Pediatric Immunology Research at major teaching hospitals and medical schools in the U.S. The Modells continue to testify before the United States Congress and have advocated before the European Union Parliament in support of increasing research funding, public awareness and physician education for Primary Immunodeficiency.

Vicki and Fred Modell have received numerous awards and recognition for their support of the Primary Immunodeficiency community including:

- The International Union of Immunological Societies (IUIS) Award at the International Congress of Immunology, in honor of contributions to the field of immunology.
Montreal, Canada
- Public Service Award from the American Association of Immunologists in recognition of their extraordinary support for and advocacy of Immunological Research,
Boston, MA
- The Canadian Immunodeficiency Society Award for Public Service,
Toronto, Canada
- The 'Century Achievement Award', from the Mt. Sinai Medical Center,
New York City, New York

Mr. OBEY. Thank you.
 Next, Madeleine Will, National Down Syndrome Society.

WEDNESDAY, MAY 12, 2010.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

WITNESS

MADELEINE WILL, VICE PRESIDENT, NATIONAL DOWN SYNDROME SOCIETY

Ms. WILL. Good afternoon, Mr. Chairman and Members of the Subcommittee. I am Madeleine Will, Vice President of Public Policy for the National Down Syndrome Society. I want to thank you for the opportunity to testify today and to thank you for your leadership role that you and the Subcommittee have played over the years in supporting and creating greater public awareness of Down Syndrome.

There are more than 400,000 people living with Down Syndrome in the U.S. and about 5,000 babies are born each year or one in 733. Down Syndrome occurs in people of all races and economic levels, and is the most frequently occurring chromosomal condition.

Mr. Chairman, recognizing the challenges the Subcommittee faces in prioritizing requests, the National Down Syndrome Society respectfully recommends that you appropriate \$5,000,000 in fiscal year 2011 to the Centers for Disease Control and Prevention to implement the requirements of the Prenatally and Postnatally Diagnosed Conditions Awareness Act which was enacted in 2008.

This law will ensure that pregnant women who receive a diagnosis of Down Syndrome and other genetic disorders prenatally or postnatally receive up to date scientific information about such things as life expectancy, functional development, clinical course, prenatal and postnatal treatment options, educational and psychosocial outcomes. This information is to be provided through the development of materials, the creation of hot lines, Web sites and informational clearinghouses.

With \$5,000,000, the Department of Health and Human Services will be able to fund, to collect and distribute information related to prenatally and postnatally diagnosed conditions.

There are several points I would like to underscore in my testimony. First, it is important to note that the organizations supporting the legislation went to great lengths to ensure bipartisan support for it, seeking out and achieving the championships of Senator Brownback and former Senator Kennedy.

We also went to considerable lengths to speak to both right to life and pro-choice groups to convey that this legislation should be characterized for what it is, a piece of legislation about accurate evidence-based information that needs to be delivered to pregnant women.

It is also important to underscore that the legislation was not designed to focus only on women who receive information about Down Syndrome. Rather, the legislation seeks to develop and to have distributed information about many disabilities and genetic disorders, to name a few: Trisomy 13 and 18, Williams Syndrome, spina bifida.

More than 1,000 prenatal tests are available or in development and a best practice bulletin has been issued by the American College of Obstetricians and Gynecologists. It is recommended that all pregnant women be offered prenatal testing, all 4 million pregnant women annually.

This means that these women need to receive information that is complex and challenging and changing with new data, advances and findings that need to be conveyed, particularly after Francis Collins' mapping of the human genome. Hank Greely, the Director of Stanford University's Center for Law and Biosciences, said recently, "Information is powerful, but misunderstood information can be powerfully bad."

Another point I would like to emphasize is that we do know how obstetricians feel about the issues of screening and the delivery of a diagnosis of Down Syndrome and other chromosomal disorders. In an article published by ACOG, 36 percent of obstetricians feel well qualified to counsel patients who screen positive for Down Syndrome; 51 percent thought the training they received was adequate, but 40 percent thought it was less than adequate; and only 29 percent of physicians surveyed provided printed educational materials to a woman when her fetus was diagnosed with Down Syndrome.

Lastly, we have information about how the diagnosis should be delivered. A 29-member research team surveyed women who had received a diagnosis to determine the best way of delivering the news, and some of the most important findings were that all women wanted to discuss all options available to them, including continuing the pregnancy, adoption and termination.

They also wanted screening results explained as a risk assessment and not as a positive or a negative result. They wanted sensitive language used in the delivery of a diagnosis and they wanted consistency in the messages conveyed by the variety of professionals with whom they interact.

NDSS is working collaboratively with ACOG, the National Society of Genetic Counselors, and the American College of Medical Genetics since the passage of the law. We have developed a consensus document which explored myths and realities about prenatal testing. We have pledged to review materials together, but frankly, we are stuck even if we had materials developed, we would not be able to move forward to publish and distribute this information to physicians and women without a Federal partner and additional funding.

Mr. OBEY. I will have to ask you to wrap it up.

Ms. WILL. Yes, Mr. Chairman, thank you for your time and attention. We are thrilled beyond measure that Congress enacted this legislation and hope that the funding of this law will lead to better information and better decision making.

Thank you.

[Written statement by Madeleine Will follows:]



Testimony Submitted by:

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Wednesday, May 12, 2010
2:00 PM - 4:30 PM
Rayburn House Office Building 2358-C

Submitted May 12, 2010 to the United States House Committee
on Appropriations Subcommittee on Labor, Health &
Human Services, Education, and Related Agencies
The Honorable Obey, Chairman

Summary of Testimony:

Ms. Will will offer testimony regarding appropriation requests for Down syndrome in Fiscal Year (FY) 2011, specifically the need to implement P.L. 110-374, the *Prenatal and Postnatal Diagnosed Conditions Awareness Act*, at the Centers for Disease Control and Prevention (CDC). The National Down Syndrome Society (NDSS) requests \$5,000,000 for the CDC to support its efforts to implement the law.



Mr. Chairman and Members of the Subcommittee:

As Vice President of the National Down Syndrome Society (NDSS), I want to take this opportunity to thank you for the leadership role this Subcommittee has played over the years in supporting and creating awareness on Down syndrome. I am pleased to offer the following testimony regarding appropriation requests for Down syndrome in Fiscal Year (FY) 2011.

There are more than 400,000 people living with Down syndrome in the U.S., and about 5,000 babies, or one in 733, that are born each year. Down syndrome occurs in people of all races and economic levels, and it is the most frequently occurring chromosomal condition. The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.

Advancements in the treatment of health problems have allowed people with Down syndrome to enjoy fuller and more active lives, and become more integrated into the economic and social structures of our communities. Unfortunately, while progress has also been made in public policies that enhance the lives of individuals with Down syndrome, barriers still exist, making it difficult for people to access adequate health care, housing, employment and education.

We have been working with Congress for decades to address these challenges and advance public policies that promote the acceptance and inclusion of individuals with Down syndrome and other genetic disorders, and help them to achieve their full potential in all aspects of their lives.

Mr. Chairman, we understand the challenges the Subcommittee faces in prioritizing requests, we believe that funding the requirements of the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007 (Public Law 110-374) is imperative given the significant impact Down syndrome has on families and communities across the country and the great potential for improvements in quality of life for them and others with chromosomal disorders. On behalf of the National Down Syndrome Society, we recommend that you appropriate ***\$5 million in the FY 2011 to the Centers for Disease Control & Prevention (CDC) to implement the requirements of the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007.***

As you know, Congress passed the *Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2007* in October of 2008. This new law seeks to ensure that pregnant women receiving a positive prenatal or postnatal diagnosis of Down syndrome will receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. Additionally, information should be provided on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational and psychosocial outcomes. The law offers referrals to support services such as hotlines, websites, and informational clearinghouses. It calls for the creation of a network of adoption registries and the strengthening of parent support networks and programs for those who receive a prenatal or postnatal diagnosis of Down syndrome or other disorders.

The intent of the law is to create a sensitive, coherent and collaborative process for delivering information about the diagnosis across the variety of medical professionals—physicians, genetic counselors, geneticists, nurses, midwives and technicians-- who currently deliver a diagnosis, to avoid any conflicting, inaccurate or incomplete information. Also, the legislation would promote the rapid establishments of links to community supports and services for parents who choose to take their baby with Down syndrome home or for those who choose to have their child adopted.

It is estimated that more than 1,000 prenatal tests are available or in development. Included among them are tests for conditions that are not life-threatening, could be helped by surgery or medical care, or don't appear until adulthood. The prognoses for people with some prenatally diagnosable disabilities have been improving markedly in recent years, leaving medical professionals scrambling to keep up with changing data and the need to communicate complex information to the over four million women who are now offered prenatal screening and testing and must weigh this information in order to give informed consent for these new procedures.

As reported in an article entitled "Changing Practice of Obstetricians", published in the *American Journal of Obstetrics and Gynecology* in April 2009, only 36% of obstetricians feel "well qualified to counsel patients who screen positive" for Down syndrome.... About half (51%) thought the training they received during residency regarding screening and diagnosis for Down syndrome was adequate, whereas 40% thought it was less than adequate and 9% thought it was comprehensive." When a fetus was diagnosed with Down syndrome only 29% of physicians provided the pregnant woman with printed educational materials.

Another study published in the *American Journal of Medical Genetics* yielded recommendations about how the diagnosis should be delivered. A 29-member research team studied the opinions of couples who had received the diagnosis to determine the best way of delivering the news and learned that mothers were emphatic that they wanted to discuss with physicians all options available to them, including continuing the pregnancy, placing the baby up for adoption

after birth, or pursuing termination¹. Studies also indicate that couples want screening results clearly explained as a risk assessment, not as a “positive” or “negative” result; they preferred to discuss all reasons for prenatal diagnosis; they preferred that results from amniocentesis or CVS, chorionic villi sampling, should, whenever possible, be delivered in person, with both parents present, if possible, or by a pre-arranged call if an in-person meeting were not possible; they desired that sensitive language should be used when delivering a diagnosis of Down syndrome and that sensitive, accurate, and consistent messages be conveyed; and contact with local Down syndrome support groups should be offered, if desired.

By including \$5 million in the FY 2011 Labor, Health & Human Services, Education, and Related Agencies Appropriations Bill, the Department of Health and Human Services (HHS) will be able to fund its responsibilities to:

- Collect and distribute information relating to Down syndrome and other prenatally or postnatally diagnosed conditions;
- Coordinate the provision of supportive services for patients receiving a positive diagnosis of a prenatally or postnatally diagnosed condition; and
- Oversee the new requirements for health care providers established by the law. The funding is also needed to carry out the requirement that the CDC assist state and local health departments to integrate testing results into surveillance systems.

Mr. Chairman, thank you for your time and attention. Given the considerable impact this condition has on families and communities across the country, the promise of further assistance and improving research outcomes for individuals with Down syndrome is crucial. We are thrilled beyond measure that Congress enacted this legislation and hope that funding this request will help to shift the way the nation regards individuals with disabilities. Through providing accurate, updated information about diagnosable conditions like Down syndrome to pregnant women, the expectation is that individuals and families will make better, more informed decisions. But the bigger impact will be better understanding on the part of the American people about the nature of disability and the value of these citizens to their families, their communities and to our country. Should you have any questions or require additional information, please feel free to call on me.

1. Skotko, B., Kishnani, P., & Capone, G. for the Down Syndrome Diagnosis Study Group (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics, Part A*, 149A: 2361-2367

¹ Skotko, B., Kishnani, P., & Capone, G. for the Down Syndrome Diagnosis Study Group (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics, Part A*, 149A: 2361-2367

MADELEINE WILL

Madeleine Will has been an advocate for persons with disabilities for three decades. She has led efforts to establish services nationally for infants and toddlers with disabilities and their families. In addition, she developed post-secondary education programs at colleges and universities, transition and supported employment programs and has promoted the concept of inclusive general education classrooms for students with disabilities,

In 2004, Ms. Will was named Director of the National Policy Center of the National Down Syndrome Society. The National Down Syndrome Society, a disability organization made up of 300 affiliates across the country, seeks to be the national advocate for the value, acceptance and inclusion of people with Down syndrome and envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

From 2002 to 2006, Mrs. Will was Chairperson of the President's Committee for People with Intellectual Disabilities (PCPID). The (PCPID) is a Federal Advisory Committee whose members are appointed by the President of the United States.

From 1989-1997, Ms. Will worked as an international consultant and developed community-based services and supports to people with disabilities in Czech Republic, Slovakia, Hungary, Russia, Bulgaria.

In 1983, Mrs. Will was appointed Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS) in the U.S. Department of Education (DOE). She assumed responsibility for management of three principal components of the DOE (Office of Special Education, the Rehabilitative Services Administration, and the National Institute on Disability and Rehabilitation Research.

In 2004, Mrs. Will received the Presidential Award for Moral and Policy Leadership from the American Association for Mental Retardation. She has received many other professional honors and special awards, including: The ARC "IDEA Hero Award"; Smith College Medal (1989); Temple University Outstanding Educator Award (1987); Federal Management Award (1986); U.S. Department of Education Secretary's Special Citation (1984).

A member of Phi Beta Kappa, Ms. Will graduated with honors and received a B.A. in history from Smith College. She also pursued graduate studies at the University of Toronto and has an M.A. in history. Mrs. Will is the parent of three children. Her son, Jonathan, has Down syndrome.

Mr. OBEY. Thank you.

I understand the situation. My nephew was a Down Syndrome child.

Next, Michael Goldberg, Society for Neuroscience.

Oh, I am sorry. I mucked up. Okay.

Gail Smith, Dr. Anthony R. Horton, International Rett Syndrome Foundation.

WEDNESDAY, MAY 12, 2010.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

WITNESS

GAIL SMITH, INTERNATIONAL RETT SYNDROME FOUNDATION

Ms. SMITH. Mr. Chairman and Committee Members, thank you for this opportunity to speak. I had a daughter with Rett Syndrome, and this is my story.

My name is Gail Smith and I reside in Maryland. My husband and I dreamed of raising a normal healthy family. Seems like yesterday when our first child was born. She was a perfect baby. She babbled and cooed her way through the first year, a bouncing happy baby. She played patty-cake and waved bye-bye and began to feed herself and walk.

Suddenly after one year old, Kristi became aloof and began to lose skills rapidly. At two and a half, she literally overnight lost her ability to walk independently. We were terrified. We pursued countless doctors and many, many medical tests, but still no answers. By five years of age, her mind was trapped within a body that would not allow her to communicate or physically respond.

We mourned the death of our normal child and began to grapple with our changing life. We experienced fear, anger and a deep sense of sadness. I used to lie in bed trembling and praying that I could just learn to cope and that she wouldn't die.

I searched fervently in medical journals and papers for any remote likeness to the symptoms that Kristi exhibited. Then one day a friend who had a daughter in some ways similar to mine shared with me a paper on Rett Syndrome. That was the first article on the condition ever published in English. I knew I had found Kristi's diagnosis.

At 13 years of age, Kristi was one of the first girls in the United States officially diagnosed with Rett Syndrome at Johns Hopkins by Dr. Andreas Rett himself. Rett Syndrome is a neurologic disorder that occurs almost exclusively in girls who develop normally until between six and 18 months of age, when the child begins a regression that severely challenges her mentally and physically.

At that time, there was no known cause, treatment or cure. Kristi spoke volumes with her eyes. She spread love with her sweet smile. She and I became symbiotic, joined at the hip. The last word she could speak was "Mama," usually when she was in stress. I became sensitive to her every need and I couldn't help her frustration or take her place from her.

She endured so many operations for scoliosis, tendon releases, and the placement of a feeding tube. As her lungs deteriorated, she

was hospitalized many times for aspiration pneumonia. I have never experienced anything as painful as watching her suffer.

On September 9, 2006, as I lay holding her in the intensive care unit at Children's National Medical Center, she slipped away. And part of me slipped away, too. She was 34 years old.

Despite the struggle, we have been so blessed to have her in our life. She has taught me more about life and relationships than any teacher I have ever had. I cry every day since she has been gone. There is a hole in my heart.

However, I am somewhat comforted knowing that she is smiling down knowing there is hope for other girls with Rett Syndrome. It is my everlasting love for Kristi and the hope for those children with Rett Syndrome, the hope that children with Rett Syndrome can be reversed for those who have the disease, and the families caring for them that brings me here today.

Research is the only way to help us find a cure for the many thousands of girls who are today suffering as Kristi did for 34 years. Through research, we have now found the cause of Rett Syndrome. Through research, we now know it can be reversed. Researchers tell us that we are at the point of testing treatments to reverse the symptoms of this disease.

With your support, we can take the next steps on the path and begin testing the therapies that will help these girls live better lives. With your support, we could reverse this disease once and for all.

I loved Kristi so much and it would mean so much to see funding appropriated to help avenge the devastating impact of this horrible disease.

Please help us. Thank you for your time and consideration.

Congressman Steny Hoyer has worked tirelessly with us on funding for Rett Syndrome. Our families met at church. He and Kristi have had a long and lasting relationship over the years. He has worked with us and has been so helpful and I want to thank him. I know he is not here.

Thank you for your time. God bless all.

[Written statements by Gail Smith and Dr. Antony R. Horton follow:]



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Testimony before the House Labor, Health and Human Services and Education
Subcommittee of Appropriations

By
Ms. Gail Smith
Parent
Kristi, MD

And

Dr. Antony R. Horton
Chief Scientific Officer
International Rett Syndrome Foundation (IRSF)

On behalf of
the International Rett Syndrome Foundation (IRSF)

May 12th, 2010

Testimony of Mrs. Gail Smith
Before the House Labor, Health and Human Services and Education
Subcommittee of Appropriations
May 12th, 2010

Mr. Chairman, Congressman Hoyer, and members of the Committee, thank you for the opportunity to testify before you today.

My name is Gail Smith and I reside in Maryland. My husband and I dreamed of raising a normal healthy family. It seems like yesterday when our first child, Kristi, was born. She was a perfect baby. When I first held her in my arms, I counted all her fingers and toes. Everything was seemingly okay. She babbled and cooed her way through the first year, a bouncy, happy baby. She played pat-a-cake and waved bye-bye, and began to feed herself and walk.

Suddenly after one year old, Kristi became aloof and began to lose skills rapidly. At 2 1/2 she literally overnight lost her ability to walk independently. The doctors were puzzled. We were terrified. For my husband, a pediatrician, it was especially frustrating. We pursued countless doctors and many, many medical tests, but still no answers.

By five years of age, everyone who had said nothing much was wrong, couldn't believe anything had ever been right. Her mind was trapped within a body that would not allow her to communicate or physically respond. We mourned the death of our normal child, and began to grapple with our changing life. We experienced fear, anger and a deep sense of sadness. I used to lie in bed trembling and praying that I could just learn to cope with the unknown. Despite the challenges, love brought me through.

I had access to medical libraries, so I searched fervently in journals and papers for any remote likeness to the symptoms that Kristi exhibited. Then one day a friend, Kathy Hunter, who had a daughter in some ways similar to mine, shared with me a paper on Rett syndrome. That was the first article on the condition ever published in English. I knew I had found Kristi's diagnosis. At 13 years of age, Kristi was one of the first girls in the United States officially diagnosed with Rett syndrome at Johns Hopkins by Dr. Andreas Rett himself.

Rett syndrome is a neurologic disorder that occurs almost exclusively in girls, who develop normally until between 6-18 months, when the child begins a regression that severely challenges her mentally and physically. At that time there was no known cause, treatment or cure.

Kristi spoke volumes with her eyes and spread love with her sweet smile. I knew she could understand certain things, recognize people and sense feelings. She cried when babies cried and flirted when she really liked someone. She and I became symbiotic, joined at the hip. The last word she could speak was "mama", usually when she was in distress. I became sensitive to her every need, but I couldn't help her frustration or take her plight from her. She endured many operations for scoliosis, tendon releases and the placement of a feeding tube. As her lungs deteriorated she was hospitalized many times

for aspiration pneumonia. I have never experienced anything so painful as watching Kristi suffer.

In 2006 Kristi slipped away from us to join the angels of heaven. She was 34 years old. Despite the struggles, we have been so blessed to have her in our lives. She has taught me more about life and relationships than any teacher I have ever had. I cry everyday since she's been gone, however, I am somewhat comforted knowing that she is smiling down on us knowing there is finally hope for others who have Rett syndrome.

It is my everlasting love for Kristi, and the hope that Rett syndrome can be reversed for those who have the disease, and the families caring for them, that brings me here today. Research is the only way to help us find a cure for the many thousands of girls who are today suffering as Kristi did for 34 years. Through research, we have now found the cause of Rett syndrome. Through research we now know it can be reversed. Researchers tell us we are at the point of testing treatments to reverse the symptoms of this disease. With your support, we can take the next steps on the path and begin testing the therapies that will help these girls live better lives. With your support, we could reverse this disease once and for all.

I loved Kristi so very much and it would mean so much to see funding appropriated to help avenge the devastating impact of this horrible disease. Please help us!

Thank you for your time and consideration. I especially want to thank Congressman Hoyer. Our families met at church, and he and Kristi shared a long and special relationship. He has worked tirelessly on behalf of Rett syndrome and rare diseases. God bless you.

Testimony of Dr. Antony R. Horton
Before the House Labor, Health and Human Services
Subcommittee of Appropriations
March 29, 2006

Mr. Chairman, Mr. Hoyer and members of the Committee, thank you for allowing me to be here today and to follow Mrs. Smith's moving testimony. My name is Dr. Antony Horton; I am the Chief Scientific Officer of the International Rett Syndrome Foundation. I am here to testify about exciting new research into the causes of Rett syndrome and to tell you that hope lies just around the corner in the form of new therapies to treat symptoms and potentially reverse this disease.

Since the discovery of the gene *MECP2* 10 years ago and because of the generous support of this subcommittee over the last several years, we have gained an enormous amount of knowledge on this unusual disorder called Rett syndrome. We now understand much more about its clinical features. We now understand much more about the fundamental details underlying this disease, and through our increasing knowledge, we have already improved the lives of individuals and families affected by this disease. For brevity's sake, you will find more of the specifics regarding the status of our research efforts in my written testimony.

Once thought to be incurable, critical research funded by our foundation, has now established the proof-of-principle that Rett syndrome is a potentially reversible disease. In concert with this discovery, over the past five years, NIH funding has allowed clinical research teams to chart the progress of this disease over time through a consortium collecting natural history data on the progression of Rett syndrome. This work is paving the way towards a targeted approach to clinical trials, by providing researchers with the resources they need to conduct more informed studies, thereby allowing them to match the right patients to the right treatments.

I am here today to ask that you continue to support this incredible progress we're making towards treatments and a cure, by funding Mr. Hoyer's request of \$500,000 for Rett syndrome which IRSF will match. These funds will be used to perform critical data collection and educational activities and directed towards crucial resources needed to investigate new medicines that have great potential to improve lives of the many people living with Rett syndrome.

Thank you all for your time.

Rett Syndrome: A Potentially Reversible Neurologic Disorder

Rett syndrome is a serious childhood neurological disorder characterized by distinctive hand movements, slowed brain and head growth, seizures, mental retardation, inability to walk correctly, breathing difficulties and a cluster of other symptoms caused by the abnormal development of the nervous system. Rett syndrome strikes randomly, it affects females almost exclusively. The course of Rett syndrome, including the age of onset and the severity of symptoms, varies from child to child. In the United States there are 4,000 diagnosed cases, however, researchers have estimated the total number of women living with Rett syndrome could be much larger with as many as 15,000 affected individuals living with the disease in the U.S. alone.

Ten years ago, with private and Federal support, researchers located the *MECP2 gene*; it was identified as the gene responsible for causing more than 90% of Rett syndrome cases. In 2007, with additional private and Federal support, researchers using an animal model of Rett syndrome successfully reversed the disease in mice, indicating potential to reverse it in humans. Genetic similarities have recently been identified between Rett syndrome and other neurological disorders such as Fragile X, autism and schizophrenia, suggesting the work accomplished so far as a private/public partnership can be applied to these different disorders.

Rett syndrome is classified as a rare or "orphan" disease, meaning that the population of patients affected by this disorder are often underserved by the pharmaceutical industry, whose financial motives direct the course of decision making in favor of targeting diseases that affect large numbers of people. To redress this balance, the United States Government has wisely opted to draft legislation that seeks to promote the development of therapies targeting underserved populations through the Orphan Drug Act.

To this end, previous funding provided by the United States Congress has been directed towards meeting the unmet needs of people living with Rett syndrome through the support of clinical trial networks and studies seeking to document the progression of the disease over time. More recently this has fostered the connection of pooled knowledge through the assembly of blue-ribbon panels of experts which included thought leaders from academia, the pharmaceutical industry, members of the National Institutes of Health and the U.S. Food and Drug Administration. The consequence of bringing together the wealth of this nation's intellectual capital has been the identification of new and existing therapies which qualify for an Orphan Drug designation. The impact of an Orphan Drug designation cannot be understated; this will bring rapid and tangible benefits to patients in tandem with academic researchers and the pharmaceutical and biotechnology industries who employ thousands of dedicated professionals that daily pursue the dream of finding cures for the diseases which in one way or another, affect us all.

With leadership from Congressman Hoyer, the support of Congress and the Centers for Disease Control, Federal funds will be used to continue the trend and build upon the success of recent discoveries. The funds we seek will augment matching funds

provided by IRSF to meet several critical needs for people living with Rett syndrome, their caregivers and professionals seeking to develop treatments and an eventual cure.

The following programs and projects will meet these needs:

Rett syndrome Natural History Study Traveling Clinics: Clinical trials are conducted to allow safety and efficacy data to be collected for the registration of therapeutic interventions (e.g., drugs, devices, therapy protocols). In order to be prepared for the implementation of clinical trials in Rett syndrome, it is important to develop accurate information on the natural history pattern of progression among individuals with Rett syndrome. The study's purpose is to gather detailed historical and physical information on a large group of females with Rett syndrome.

Enrollment was initiated in March, 2006. Because of Federal support, hundreds more have been enrolled in the study. At present, there are well over 800 participants. Without this support the study would not have achieved the current enrollment success. Ongoing support for the Traveling Clinics fulfills a dual role by facilitating the rapid recruitment and ongoing retention of patients enrolled in the Natural History study and offers specialized medical advice for families and caregivers. This is only achieved by bringing this leading team of clinical experts to meet patients they would otherwise never see.

Rett syndrome Patient Registry & Informational Databases: Federal support of a Patient Registry helps avoid delay in bringing treatments to those afflicted with this disease. Because patients self-identify it improves the ability of researchers to recruit sufficient numbers of candidates that meet the entrance criteria of a clinical trial. Many rare disease organizations are designing patient registries and clinical systems to identify patients for clinical trials and to provide research data for investigators. Gathering data from patients, clinicians and other databases is an essential step in building clinical trials. The informational databases currently supported by IRSF will be combined under the aegis of a unified Patient Registry. Since, small populations of individuals are affected by rare diseases; this requires the collection of patient information on a global scale. Federal support of these databases permits the identification of subsets of Rett syndrome patients enabling clinical investigators to target drug therapies to the patients' individual genotypes. This tailor-made approach to treatment both maximizes efficacy while minimizing the adverse effects of a drug by matching the right patient to the right treatment.

RettSearch Clinical Research Consortium: Federal support has allowed for vast improvements in the collection of scientific information on clinical aspects of the disease. The RettSearch International Clinical Research Consortium is coordinated through a central hub based at the Kennedy Krieger Institute, at Johns Hopkins University in Baltimore, Maryland. This is the coordinating center for all Rett syndrome clinical research conducted across the globe. This clearing house of information has led to reduced duplication and increased effectiveness of research efforts. Its mission is to promote the development of new approaches for the treatment of Rett syndrome,

develop guidelines for medical practitioners, collect and disseminate information in areas of relevance to clinical research and to coordinate clinical trials with newly emerging therapies for Rett syndrome.

Meeting on Therapeutics for Rett syndrome and Related Autism Spectrum Disorders: Federal support for meetings such as this enables IRSF to gather scientists and clinicians with varying areas of expertise to stimulate and exchange new ideas, combine skills, disciplines and resources. This has already resulted in a vast network of individuals working in tandem to strategize facilitating the discovery, development and testing of new treatments and advancing them to patients with Rett syndrome and other related neurodevelopmental disorders, thereby accelerating the drug discovery process. Meetings such as this greatly foster cross-disciplinary collaborations and inform researchers where treatments that are in development for one disorder could be applied to aid patients suffering with a similar condition.

The proposed workshop will convene a group of leading scientific researchers working on Rett syndrome and other autism spectrum disorders (ASDs) which together, are known to affect 1:110 individuals. The meeting will seek to involve other patient advocacy groups within the Autism Spectrum who are seeking treatments for related diseases such as Fragile-X syndrome, Tuberous Sclerosis, Angelman syndrome and Prader-Willi syndrome as well as classic autistic disorder. Presently, there are few opportunities for specialists to focus on translating research discoveries from various disorders with the specific goal of informing others of new therapies to treat these diseases.

Medical Education & Family Support: Through education and support American families touched by Rett syndrome can take advantage of the most recent information and developments in the field and serve as advocates for their children and their treatment with the medical community. Rett syndrome is a rare, complex neurologic disorder affecting 1:10,000-15,000 females; most physicians and specialists will never encounter an individual with Rett syndrome in their practice. Since the majority of Rett syndrome patients are severely handicapped and nonverbal, they cannot independently communicate the status of their health, pain or illness. IRSF is a trusted source of vetted, expert medical advice via electronic and print media for families, caregivers, and health providers seeking assistance during a health or medical crisis. This helps to remove barriers to good health for the affected individuals and the families, caregivers, health providers and general public who support and live with those diagnosed with Rett syndrome.

We seek your support to continue our vital work.

Antony Horton PhD
 IRSF (NY Office)
 260 Madison Ave (# 8051)
 New York, NY 10016

phone: 917 267 4302
 cell: 917-365-7484

ahorton@rettsyndrome.org

EMPLOYMENT HISTORY:

Chief Scientific Officer

2008 - present: *International Rett Syndrome Foundation, New York, NY*

- Provide direction and oversight for research programs on Rett Syndrome
- Liaise with industry, academia, Government and non- governmental agencies

Director of Scientific Affairs

2006 – 2008: *Alzheimer's Drug Discovery Foundation, New York, NY*

- Provided oversight of research program in Alzheimer's disease and related dementias
- Liaised with industry, academia, Government and non- governmental agencies
- Developed "Venture Philanthropy" programs to seed fund new biotech companies

Program Director, Diabetes Complications

2004 – 2006: *Juvenile Diabetes Research Foundation, New York, NY.*

- Oversaw \$30M research program on diabetic complications.
- Initiated and developed drug screening program for diabetic complications.
- Developed clinical research initiatives in diabetic nephropathy and retinopathy.
- Developed complications therapeutics within industrial and academic setting.
- Worked with several Government agencies (U.S. and overseas) setting scientific policy.

Scientific Program Manager

2001 – 2004: *Juvenile Diabetes Research Foundation, New York, NY.*

- Oversaw grant review and complications research study section.
- Pro-Actively managed research program.
- Developed and ran meetings and workshops in topic specific areas.
- Scientific liaison between JDRF, Government and Academic scientists.
- Scientific consultant for JDRF media department.

Post Doctoral Scientist – Nathaniel Heintz Lab Head

1998 – 2001: *Rockefeller University, Lab. Of Molecular Biology, New York NY*

- Conducted Post-doctoral research on neurodegeneration in the CNS
- Learned laboratory techniques in molecular cloning
- Taught other scientists cell biology techniques (microdissection, primary cell culture)
- Gave seminars and published research in leading peer reviewed academic journals

EDUCATION

1993 – 1997 *St. Andrews University, Scotland, UK*

- Doctor of Philosophy (Ph.D.) in developmental neurobiology
- Area of research: cell survival and cell death in the developing vertebrate nervous system.

1987 – 1990 *Kingston University, London UK*

- Bachelor of Science (B.Sc. Hons) in Biochemistry / Analytical Chemistry

SCIENTIFIC PUBLICATIONS:

Yue Z*, **Horton A***, Bravin M, DeJager P, Selimi F., Heintz N (***Primary Author**)

A Novel Protein Complex Linking the $\delta 2$ Glutamate Receptor and Autophagy: Implications for Neurodegeneration in Lurcher Mice. *Neuron*; **35** (5): 921-33 (2002)

Horton A, Bartlett PF, Pennica D, Davies AM.

Cytokines promote the survival of mouse cranial sensory neurones at different developmental stages. *Eur. J Neurosci*; **10** (2):673-9 (1998)

Horton A, Laramée G, Wyatt S, Shih A, Winslow J, Davies AM. *NGF binding to p75 enhances the sensitivity of sensory and sympathetic neurons to NGF at different stages of development.* *Mol Cell Neurosci*; **10** (3-4):162-72 (1997)

Buj-Bello A, Adu J, Pinon LG, **Horton A**, Thompson J, Rosenthal A, Chinchetru M, Buchman VL, Davies AM. *Neurturin responsiveness requires a GPI-linked receptor and the Ret receptor tyrosine kinase.* *Nature*; **387**:721-4 (1997).

Buj-Bello A, Buchman VL, Horton A, Rosenthal A, Davies AM

GDNF is an age-specific survival factor for sensory and autonomic neurons. *Neuron*; **15** (4):821-8 (1995).

Davies AM, **Horton A**, Burton LE, Schmelzer C, Vandlen R, Rosenthal A

Neurotrophin-4/5 is a mammalian-specific survival factor for distinct populations of sensory neurons. *J. Neurosci*; **13** (11):4961-7 (1993).

Augenstein K, Lane JB, **Horton A**, Schanen C, Percy AK.

Variable phenotypic expression of a MECP2 mutation in a family. *J Neurodev Disord.* Dec; **1**(4):313. (2009)

PUBLISHED REVIEW ARTICLES & ABSTRACTS:

Horton A., Fillit H "Drug Discovery for Alzheimer's Disease: Filling the Pipeline" *Current Alzheimer Research*, 2007, Vol. 4, No. 5 501 (2008)

8th Annual EASD/JDRF Oxford Workshop 2003, "Prediction and Early Detection of Diabetic Complications: Common Pathways and Unique Needs" (Meeting report prepared on behalf of EASD). *Diabetologia*; **47** (4) R 35 -47(2004)

7th Annual EASD/JDRF Oxford Workshop 2002, "New Frontiers in the Treatment and Prevention of Type 1 Diabetes and its Complications" (Meeting report prepared on behalf of EASD). *Diabetologia*; **45** (11): R70-80, (2002)

Horton A, DeJager P, Bravin M, Heintz N.

A novel glutamate receptor $\delta 2$ interacting protein. *Soc. Neurosci. Abs.*; **25** (1): 510.19 (1999)

Horton A, Davies AM, Buj-Bello A, Bartlett P, Murphy M.

Leukemia inhibitory factor and ciliary neurotrophic factor in sensory neuron development. *Perspectives on Developmental Neurobiology*; **4** (1) : 35-8 (1996).

PROFESSIONAL SOCIETY MEMBERSHIPS:

Society for Neuroscience – Member since 2006

New York Academy of Sciences (NYAS) Member since 2006

American Society for Experimental Neuro-Therapeutics (ASENT) – Member since 2006

Mr. OBEY. Thank you. I know it is tough to bring that story here. Next, Michael Goldberg, Society for Neuroscience.

WEDNESDAY, MAY 12, 2010.

NATIONAL INSTITUTES OF HEALTH

WITNESS

MICHAEL E. GOLDBERG, M.D., PRESIDENT, SOCIETY FOR NEUROSCIENCE

Dr. GOLDBERG. Mr. Chairman and Members of the Committee, it is an honor to testify today on the fiscal year 2011 budget.

On behalf of the 40,000 scientists and clinicians who are members of the Society for Neuroscience, I thank the Subcommittee for its past support of research at the NIH and in particular I thank Chairman Obey for his unflagging support for biomedical science.

I am Michael Goldberg, President of the Society for Neuroscience, and the David Mahoney Professor of Brain and Behavior at Columbia University in New York. Because I am both a basic neuroscientist and an active clinical neurologist, I know how basic research translates to new and better treatments for human disease often in unexpected ways.

On behalf of the Society, I respectfully request a 2011 NIH appropriation of \$35,000,000,000. This level will sustain the burst of scientific productivity funded by the American Recovery and Reinvestment Act for which the scientific community thanks this Congress and the Obama Administration, and which was especially welcome after six years of below inflationary increases for NIH.

ARRA funding was an unqualified success. Areas of research that need to be sustained include the application of genetic knowledge to clinical treatment, immunological treatments for addiction, and the understanding of memory loss in Alzheimer's and in normal aging.

While we applaud President Obama's strong commitment to science, the Administration's fiscal year 2011 budget does not fully take into account the tremendous scientific momentum from ARRA. With continued funding at the ARRA-adjusted base of \$35,000,000,000, this research will form the foundation for new medical applications. Without it, NIH will see the wasteful termination of promising research programs just begun under ARRA funding and the firing of thousands of technicians and research fellows. Young investigators, the future of American science, will be especially devastated. Ultimately, scientific progress on diseases that cost society trillions will be delayed or derailed.

In addition, strong NIH funding is vital to ensure that the United States remains the world leader in biomedical research. Today, that role is being threatened. For instance, China's government is using financial resources to draw scientists home. In my own lab, a post-doctoral fellow with a green card received an offer from the Chinese government that could not be matched in America, given the current funding climate, and he went back to China.

SFN supports a robust international scientific community, yet we understand that strong American leadership is vital both to catalyze global research and to protect our Nation's future.

Finally, as an NIH-funded scientist, funded by the National Eye Institute, I not only conduct research relevant to autism and attention deficit disorder, I support a community of workers. More than three-quarters of my funding goes to hire fellows, machinists, computer scientists, biological technicians and animal caretakers, as well as administrative staff.

Nationwide, robust NIH funding generates hundreds of thousands of high wage jobs in every American State. According to a recent report, every \$1 in NIH funding adds \$2.11 to our economy.

In closing, I stress that today, we live on the forefront of an era of breathtaking potential to advance biological knowledge and human health. And we are all fortunate to have the NIH, the world's finest biomedical research enterprise and a strong economic engine for America. As the Nation considers difficult decisions in the face of economic strain, prioritizing strong NIH funding remains a wise investment precisely because it contributes to our health and our economic strength.

As the Nation emerges from recession, ARRA's infusion in infrastructure, labs, people and discoveries should be made permanent to serve the American people, their health and our economy.

On behalf of the Society for Neuroscience, I again thank this Subcommittee, its Chair, and the Nation for America's commitment to research. I urge you to sustain the momentum with a fiscal year appropriation of \$35,000,000,000.

Thank you, Mr. Chairman.

[Written statement by Michael E. Goldberg, M.D., follows:]

SOCIETY FOR NEUROSCIENCE

Wednesday, May 12, 2010
2:00 PM to 4:30 PM

Witness appearing before the
House Subcommittee on Labor – HHS – Education Appropriations

Michael E. Goldberg M.D.
President, Society for Neuroscience
David Mahoney Professor of Brain and Behavior in the Departments of Neuroscience, Neurology,
Psychiatry, and Ophthalmology
Columbia University College of Physicians and Surgeons
New York, NY

Dr. Goldberg will testify on the health and economic benefits of research funded by the National
Institutes of Health and will make a request for fiscal year 2011 appropriations.

Written Public Witness Testimony
Michael E. Goldberg, President
Society for Neuroscience
(202) 962-4000, advocacy@sfn.org

Submitted to the
House Subcommittee on Labor, Health and Human Services, Education, & Related Agencies
FY 2011 National Institutes of Health
April 14, 2010

Introduction

Mr. Chairman and Members of the Subcommittee, I am Michael E. Goldberg, M.D. I am the David Mahoney Professor of Brain and Behavior, in the Departments of Neuroscience, Neurology, Psychiatry, and Ophthalmology; as well as the Director of the Mahoney-Keck Center for Brain and Behavior Research at Columbia University and President of the Society for Neuroscience (SfN). My area of specialization is the physiology of cognitive processes: visual attention, spatial perception, and decision making.

On behalf of the 40,000 members of the Society for Neuroscience, I would like to thank you for your past support of neuroscience research at the National Institutes of Health (NIH). Research funded by NIH has returned significant dividends in terms of improved patient care as well as the development of prevention programs for brain and nervous system disorders. In this testimony, I will highlight how taxpayers have benefited from this investment, and how a sustained investment can enhance medical research, health, and economic strength.

Fiscal Year 2011 Budget Request

The entire scientific community is deeply grateful for the historic investment in NIH through the American Recovery and Reinvestment Act (ARRA), which is now funding high quality research, while creating and preserving jobs. This investment in innovation and science is not only setting a path to new discoveries, but also helping to stimulate the national and local economies, preserving or creating an estimated 50,000 new high-wage, hi-tech jobs at a critical time for U.S. research, and producing an estimated 2.5 return on investment for local communities. **To continue this exciting scientific and economic momentum and maintain the current research capacity, the Society respectfully requests that Congress provide a fiscal year 2011 appropriation in the amount of \$35 billion for NIH.** This level of funding will build on the research activities supported by the regular 2010 appropriations and ensure that the nation's universities do not lose scientific ground, and be forced to lay off thousands of U.S. scientists and their support staffs, when the ARRA funding ends this year. A strong investment in the scientific enterprise will ensure that there is not a dramatic drop in research activity and more job losses, as well as serve strong encouragement to keep our young researchers in the training pipeline and keep the programmers, technicians, and engineers so critical to biomedical research in their jobs.

What is the Society for Neuroscience?

The Society for Neuroscience (SfN) is a nonprofit membership organization of basic scientists and physicians who study the brain and nervous system. SfN's mission is to:

1. Advance the understanding of the brain and the nervous system.
2. Provide professional development activities, information, and educational resources for neuroscientists at all stages of their careers.
3. Promote public information and general education about the nature of scientific discovery and the results and implications of the latest neuroscience research.

4. Inform legislators and other policymakers about new scientific knowledge and recent developments in neuroscience research and their implications for public policy, societal benefit, and continued scientific progress.

What is Neuroscience?

Neuroscience is the study of the nervous system—including the brain, the spinal cord, and networks of sensory nerve cells, or neurons, throughout the body. Humans contain roughly 100 billion neurons, the functional units of the nervous system. Neurons communicate with each other by sending electrical signals long distances and then releasing chemicals called neurotransmitters which cross synapses—small gaps between neurons.

The nervous system consists of two main parts. The central nervous system is made up of the brain and spinal cord. The peripheral nervous system includes the nerves that serve the neck, arms, trunk, legs, skeletal muscles, and internal organs.

Critical components of the nervous system are molecules, neurons, and the processes within and between cells. These are organized into large neural networks and systems controlling functions such as vision, hearing, learning, breathing, and, ultimately, all of human behavior.

Through their research, neuroscientists work to:

- Describe the human brain and how it functions normally.
- Determine how the nervous system develops, matures, and maintains itself through life.
- Find ways to prevent or cure many devastating neurological and psychiatric disorders.

NIH-Funded Brain Research Successes

The funds provided in the past have helped neuroscientists make significant progress in diagnosing and treating neurological disorders. Today, thanks to NIH-funded research, scientists and health care providers have a much better understanding of how the brain functions.

The following are a few of the many success stories in neuroscience research:

- **Post-Traumatic Stress Disorder (PTSD)** – For years it was thought that those who survived or witnessed a trauma should be able to tough it out and move on. But scientific studies funded by the NIH helped reveal that PTSD is a serious brain disorder with biological underpinnings. Health care practitioners today are better able than ever to help those who have suffered a traumatic event to cope, thanks to research over the past 20 years. Yet much remains to be done, and this research must continue aggressively in light of returning veterans' health care needs in coming generations. NIH-funded studies on the brain chemicals and structures altered in PTSD offer particular hope for developing effective treatments. One approach is to target the corticotrophin-releasing factor (CRF), a brain chemical that plays a crucial role in coordinating the body's response to stress. And NIH-funded studies showed that drugs called selective serotonin reuptake inhibitors improved the memory of patients with PTSD and reduced shrinkage of brain tissue in the part of the brain involved in memory and emotion, helping PTSD patients better deal with traumatic memories.
- **Age-Related Macular Degeneration** – As you grow older, you may some day notice your vision becoming blurry or distorted. Straight lines appear wavy, and it becomes more difficult to recognize familiar faces. These signs may point to age-related macular degeneration, or AMD, the leading cause of blindness and vision impairment among older Americans. AMD is a form of neurodegeneration that affects the light-sensitive nerve cells in the retina at the back of the eye. AMD causes nerve cells in the macula, the central

region of the retina, to break down, and abnormal deposits accumulate beneath the retina. Many elderly people with AMD become socially isolated from friends and family and can no longer participate in the activities they once enjoyed. Thanks to work supported by NIH, scientists have made rapid advances in understanding AMD and are beginning to develop new treatments. Getting older remains the strongest risk factor, but scientists now know that AMD results from a complex interaction among genetic and environmental factors. For example, smoking increases the risk. One recent NIH study found that supplementing the diet with high levels of antioxidants and zinc reduced patients' risk of developing the advanced form of AMD disease by about 25 percent. The first drug to treat AMD was approved by the FDA in 2000. When this drug is activated by the application of laser light, it eliminates the faulty blood vessels underneath the retina and reduces further loss of vision. Doctors also may treat the disease directly with laser surgery, destroying new blood vessels and sealing leaks. Scientists have found important similarities between deposits that form in the eye in AMD and deposits in the brain in age-related neurodegenerative diseases such as Alzheimer's and Parkinson's. The deposits are found in some types of kidney disease as well. Because the effects of treatments are easier to visualize in the eye, studies of AMD may lead to improved treatment of these other diseases.

- **New Treatments From Nature's Poisons** – Neuroscientists have uncovered an unlikely source of new treatments for neurological disorders and diseases—the toxins and venoms of fish, snails, frogs, scorpions, and other creatures of land and sea. Brain researchers are finding that what makes these poisonous substances dangerous in the wild may also make them useful tools in the clinic. Already, they are helping to relieve chronic pain, and they may one day prove effective in treating brain cancer. One deadly venom—that of the giant yellow Israeli scorpion aptly nicknamed the “deathstalker”—is being studied as a possible tool in the treatment of glioma, the most common type of brain tumor. Each year, about 22,000 Americans are diagnosed with this quickly spreading cancer, and many die within 12 months. Glioma cells spread throughout the brain, including into its narrowest spaces, with the help of special ion channels not found in healthy brain cells. A chemical in the deathstalker's venom, chlorotoxin, binds to these ion channels, an action that slows down the cancer's growth without harming nearby healthy cells. Other research suggests that chlorotoxin may be able to help kill gliomas and perhaps other cancerous tumors through a different mechanism—by shutting off their blood supply. A non-narcotic synthetic form of a poisonous compound found in the venom of cone snails is already helping to relieve chronic neuropathic pain in humans. Neuroscientists are currently investigating whether other chemicals in cone snail venom might help block the surge of electrical brain activity that triggers epileptic seizures.

The above success stories required a close working collaboration between the basic researcher discovering new knowledge and the clinical-physician researcher translating those discoveries into new and better treatments. Much other research in neuroscience is dedicated to understanding basic phenomena, which, although motivated by clinical problems, are not yet at the stage where they can be translated into cures. For example, patients with lesions in the parietal lobe, a part of the cerebral cortex, are devastated by deficits in visual attention and spatial perception. NIH-supported research in my own laboratory has illuminated much of the signal processing by which the parietal lobe enables subjects to locate objects in space and attend to them. We now understand why patients with parietal lesions behave as they do; helping them is the next step. Other groups in the Mahoney-Keck Center at Columbia University are doing NIH-supported research into the basic mechanisms of how subjects assign value to objects in the world, and make choices based on that value. A clinically relevant example of these processes is the question of why a drug addict assigns high value to drugs and then decides to acquire them. This research will illuminate the neurobiology of processes like drug-seeking, and may lead to better treatment,

Conclusion

The field of neuroscience research holds great potential for addressing the numerous neurological illnesses that strike more than 50 million Americans annually. As noted by my institution's (Columbia University) Mind, Brain

and Behavior Initiative: "In the 20th century, scientists discovered a great deal about the brain. They discovered what happens to individual neurons when memories are made and created powerful tools to image brain function. But while they made great strides toward understanding molecules, cells, and brain circuitry, scientists continue to unearth how these circuits come together in systems to record memories, illuminate sight and produce language. We have entered an era in which knowledge of nerve cell function has brought us to the threshold of a more profound understanding of behavior and of the mysteries of the human mind. Many believe that the next level of understanding will come from analyses not of single cells but of ensembles of neurons whose concerted actions must underlie the complexity of human behavior and thought. Neural circuits must, in some way, account for high-level functions such as memory, self-awareness, language, joy, depression, and anger. Taking this research to the next level through collaborations with the social sciences will illuminate and identify the role of social interactions in normal and abnormal brain function..." However, this can only be accomplished by a consistent and strong funding source.

An NIH appropriation of \$35 billion for fiscal year 2011 is required to take this research to the next level in order to improve the health of Americans and to sustain the nation's global competitiveness. Additionally, the new research capacity must be sustained to realize the scientific outcomes initiated by the Recovery Act dollars and to ensure the next generations of scientists will have opportunities in research. A strong scientific investment not only produces ground breaking medical treatments and discoveries; it supports national economic recovery, by creating thousands of jobs and forming the foundation for a stronger national economy based on technology and innovation.

Thank you for the opportunity to submit this testimony.

Sincerely,

Michael E. Goldberg, M.D.
President, Society for Neuroscience
David Mahoney Professor of Brain and Behavior
Departments of Neuroscience and Neurology
Columbia University College of Physicians and Surgeons

| BIOGRAPHICAL SKETCH | | | |
|--|---------------------------|---|------------------------|
| NAME Goldberg, Michael E. | | POSITION TITLE David Mahoney Professor of Brain and Behavior in the Departments of Neuroscience, Neurology, Psychiatry, and Ophthalmology, Columbia University College of Physicians and Surgeons | |
| eRA COMMONS USER NAME (credential, e.g., agency login) GOLDBERGME | | | |
| EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as nursing, and | | | |
| INSTITUTION AND LOCATION | DEGREE (if applicable) | YEAR(s) | FIELD OF STUDY |
| Harvard College | A.B. | 1959-1963 | Biochemical Sciences |
| Harvard Medical School | M.D. | 1964-1968 | Medicine |
| Harvard Longwood Program in Neurology | | 1972-1975 | Residency in Neurology |

Selected Experience and Honors: Consultative:

- 2007 - Ad hoc member, Board of Scientific Counselors, NIMH
 2009 - Member, Board of Scientific Reviewers, Howard Hughes Medical Institute
 2010 - Advisory Board, CNRS Unit on Cognitive Neuroscience, Marseille

Selected Positions in scientific societies:

- 1992-1996 President, International Neuropsychological Symposium.
 1996-1998 Trustee, Neural Control of Movement Society
 2008-2011 President-elect, President, then Past President Society for Neuroscience

Selected Honors: Member, Phi Beta Kappa (1963), Alpha Omega Alpha (1968)

- 1972 S. Weir Mitchell Award, American Academy of Neurology
 1982 Elected to the American Neurological Association
 1997 Elected an Associate of the Neuroscience Research Program of the Neuroscience Institute.
 1999 Wundt Lecturer, Max Planck Institute for Cognitive Neuroscience, Leipzig
 1999 Graduation Visiting Professor of Neurology, Longwood Program, Harvard Medical School.
 2000 Sprague Lecturer, Mahoney Neuroscience Institute, University of Pennsylvania
 2002 Heller Lecturer in Computational Neuroscience, Hebrew University, Jerusalem, Israel.
 2004 Mary G. Natter Lecturer in Neurobiology, University of Rochester
 2006 Bodian Lecturer, Johns Hopkins University
 2006 Elected a Fellow of the American Academy of Arts and Sciences
 2008 Elected a Fellow of the American Association for the Advancement of Science
 2010 David Robinson Lecturer, Department of Biomedical Engineering, Johns Hopkins

Peer-reviewed publications (in chronological order, selected from 75).

1. Wurtz, R.H. and Goldberg, M.E. Superior colliculus cell responses related to eye movement in awake monkeys. *Science* 171: 82-84, 1971.
2. Bisley, JW and Goldberg, M.E. Neuronal Activity in LIP and Spatial Attention. *Science*, 299:81-86, 2003.
3. Ipata AE, Gee AL, Bisley, JW and Goldberg, ME. Responses in the lateral intraparietal area to a popout stimulus are reduced if it is overtly ignored. *Nat. Neurosci.*, 9:1071-6.
4. Wang X, Zhang M, Cohen IS, Goldberg ME. The proprioceptive representation of eye position in monkey primary somatosensory cortex. *Nature Neuroscience* 10:640-6, 2007.
5. Bisley, JW and Goldberg, ME Saccades, Attention, and Priority in the Parietal Lobe. *Annu. Rev. Neurosci.* In Press.

Current NIH Support (grants for which Goldberg is PI, direct costs are annual)

- 1 R01 EY014978-06 The Neurophysiology of Spatial Vision 8/1/2009-7/30/2014 \$250,000 direct costs
 1 R01 EY017039-02 The neurophysiology of visual search, 5/1/08-4/30/2013 \$250,000 direct costs
 1P30 EY019007-01 Core Grant for Vision Research 7/1/2010-6/30/2015
 (although I have not received an NGA, I have been assured by the program officer that the grant will be funded at a level between \$400,000 and \$500,000 annual direct costs).

Mr. OBEY. Thank you.
Next, Cynthia Bearer, Children's Environmental Health Network.

WEDNESDAY, MAY 12, 2010.

**DEPARTMENT OF HEALTH AND HUMAN SERVICES,
CLEAN GREEN AND HEALTHY SCHOOL INITIATIVE**

WITNESS

CYNTHIA BEARER, M.D., BOARD CHAIR, CHILDREN'S ENVIRONMENTAL HEALTH NETWORK

Dr. BEARER. Good afternoon. Thank you for the opportunity to testify before you today.

I am the Mary Gray Cobey Professor of Neonatology and Division Chief of Neonatology at the University of Maryland. However, I am not here today in that role, but in my role as Board Chair for the Children's Environmental Health Network.

The Network is a nonprofit organization that has been working for almost 20 years to promote a healthy environment and to protect all children from environmental health hazards.

The world in which today's children live has changed tremendously from that of previous generations. This includes a phenomenal increase in the number of new substances to which children are exposed. For example, my 13-year-old son Matt has already been exposed to many more chemicals than I was at his age. Most of these chemicals are untested in their effects on developing organ systems such as the brain.

Children have unique vulnerabilities and susceptibilities to toxic chemicals. As we have learned from lead, mercury and alcohol, an exposure which may cause little or no harm to an adult may cause permanent harm to a child. The Network appreciates the wide range of needs that you must consider here for funding. We urge you to give priority to those programs that directly protect and promote children's environmental health. In so doing, you improve not only our children's health, but also their educational outcomes and their future.

My written testimony provides information on the funding needs of a variety of agencies and collaborative programs that are key in protecting children's environmental health, such as the Children's Environmental Health Research Centers of Excellence; the National Environmental Public Health Tracking Program; and the National Children's Study.

The Network urges the Committee to provide full funding for the Administration's Clean Green and Healthy School Initiative. As you know, school children and their parents do not have an OSHA. No agency is authorized to intervene to protect children from environmental hazards in schools. We require our children to spend hours in an environment where they and their parents have no recourse if that environment is not healthy.

Unfortunately, studies have shown that many of our school buildings are unhealthy. Similarly, although millions of preschool children spend hours in day care, most State licensing programs include few environmental health standards. Thus, we urge the Com-

mittee to expand the Clean Green and Healthy Schools Initiative to include child care.

I will close by mentioning an area that has been of great concern to the Network, but which has received little attention by policymakers. I am referring to global climate change. Of course, climate change has been a hot topic. However, the health impacts of climate change, especially the health impact on children, have received almost no attention. Yet children as a vulnerable sub-population will be the first and worst hit by climate change.

The World Health Organization estimates that more than 150,000 deaths per year due to climate changes are already occurring in the world's low-income nations. Of these deaths, almost 85 percent are young children. Thus, the Network urges the Committee to provide \$50,000,000 in fiscal year 2011 for the Department of Health and Human Services to prepare for the potential health effects of global climate change.

In conclusion, investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures, an outcome we can all support. That is why the Network asks you to give priority to these programs.

Thank you.

[Written statement by Cynthia Bearer, M.D., follows:]

Testimony submitted by
Cynthia Bearer, M.D., Ph.D., FAAP
Board Chair
The Children's Environmental Health Network
Washington, DC 20002

Dr. Bearer is Mary Gray Cobey Professor and Division Chief of Neonatology at the University of Maryland but she is appearing today on behalf of the Children's Environmental Health Network.

Subcommittee on Labor, Health & Human Services, Education and Related Agencies
House Committee on Appropriations
Appropriations for Fiscal Year 2011
May 12, 2010, 2 pm

Summary: Dr. Bearer will testify in support of the activities and programs in the Departments of Health & Human Services and Education that protect children from environmental hazards:

- **Global Climate Change and Public Health:** \$50 million to HHS to help the public prepare for and adapt to the health effects of global climate change
- **Centers for Disease Control and Prevention (CDC):** \$8.8 billion for CDC's core programs
- **National Center for Environmental Health (NCEH):** Support for all programs, especially its biomonitoring program and its national report card on exposure information
- **The Environmental Health Laboratory:** A \$19.6 million increase
- **National Environmental Public Health Tracking Program:** \$50 million
- **National Institute of Environmental Health Sciences (NIEHS):** \$779.4 million
- **Children's Environmental Health Research Centers of Excellence:** Reinstate last year's funding increase and direct NIEHS to sustain this effort.
- **National Children's Study (NCS):** Provide full funding, and assure that the NCS remains a collaborative study that retains on its original environmental focus and require that protocols are in place for measuring exposures in child care and school settings.
- **Pediatric Environmental Health Specialty Units (PEHSUs):** \$1.8 million as ATSDR's portion of this program
- **Environmental Health in Schools:** Full funding for the Clean, Green and Healthy Schools Initiative and resources for the newly re-vitalized Interagency Task Force on Children's Environmental Health.
- **Environmental Health in Child Care Settings:** Require that the child care environment is included in the Clean, Green and Healthy Schools Initiative and provide additional resources to support this. Direct the HHS Assistant Secretary for Children and Families to report on the Administration for Children and Families (ACF) activities that protect children from environmental hazards in child care settings, especially in the Office of Head Start.



CHILDREN'S ENVIRONMENTAL HEALTH NETWORK
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Testimony of Cynthia Bearer, M.D., Ph.D., FAAP
 CEHN Board Chair
 May 12, 2010

Thank you for the opportunity to testify before you today. I am the Mary Gray Cobey Professor and Division Chief of Neonatology at the University of Maryland; however my testimony today is not on behalf of the University. I am here today in my role as Board Chair of the Children's Environmental Health Network

The Network appreciates the wide range of needs that you must consider for funding. We urge you to give priority to those programs that directly protect and promote children's environmental health. In so doing, you will improve not only our children's health, but also their educational outcomes and their future.

The Network is a national organization whose mission is to promote a healthy environment and to protect the fetus and the child from environmental health hazards. The world in which today's children live has changed tremendously from that of previous generations, including a phenomenal increase in the substances to which children are exposed. Every day, children are exposed to a mix of chemicals, most of them untested for their effects on developing systems. In general, children have unique vulnerabilities and susceptibilities to toxic chemicals. In some cases, an exposure which may cause little or no harm to an adult may lead to irreparable damage to a child.

Thus it is vital that the Federal programs and activities that protect children from environmental hazards receive adequate resources. The key programs in your jurisdiction are listed below.

Global Climate Change and Public Health

We strongly urge the Committee to designate \$50 million for HHS to help the public prepare for and adapt to the potential health effects of **global climate change** in FY2011.

Global climate change presents major challenges to public health. **Children, as a vulnerable subpopulation, will be the first and worst hit by climate change.** Young children are almost 85% of the estimated 150,000+ climate change-related deaths/year that are already occurring in low income nations, according to the World Health Organization. Children in communities that are already disadvantaged will be the most harmed. Recent studies have detailed the multiple ways in which climate change may harm children.

It is imperative that the Federal government undertake efforts to mitigate and adapt to climate change. Providing funding to the relevant HHS agencies to prepare for the potential health effects of global climate change is an important step.

Centers for Disease Control and Prevention (CDC) and the National Center for Environmental Health (NCEH)

The CDC is the nation's leader in health promotion and disease prevention, and should receive top priority in federal funding. CDC continues to be faced with unprecedented challenges and responsibilities. The Network is grateful for your support in the past and urges you to support a funding level of \$8.8 billion for CDC's core programs in FY 11.

The Network is supportive of all NCEH programs and especially its efforts to continue and expand its biomonitoring program and to continue its national report card on exposure information. A vital CDC responsibility in pediatric environmental health is to assist in filling the major information gaps that exist about children's exposures. The Network believes it is especially critical for the NCEH to gather and publish expanded information in the report card on children's exposures.

CEHN strongly supports increased funding for CDC's Environmental Health Laboratory, which allows us to measure with great precision the actual levels of more than 450 chemicals and nutritional indicators in people's bodies. This information helps public health officials to determine which population groups are at high risk for exposure and adverse health effects, assess public health interventions, and monitor exposure trends over time.

In just this past year, CDC has worked with state health departments, academic partners and others to provide exposure information for more than 50 public health investigations and studies. It has also published the *Fourth National Report on Human Exposure to Environmental Chemicals*, which presents exposure information for 212 environmental chemicals. CDC has also been able to fund three states for state biomonitoring activities. We enthusiastically support these state biomonitoring efforts, but were disappointed that another 21 quality state proposals were turned down due to lack of funding.

Unfortunately, the President's FY 11 budget would cut this program by \$1.3 million. The Network supports a \$19.6 million increase for CDC's Environmental Health Laboratory in FY 11: \$10 million to fund 7-10 grantees to conduct biomonitoring; \$7.6 million for intramural activities, including increasing the number of chemicals CDC measures and improving quality assurance at the state laboratories awarded biomonitoring funds; and \$2 million for the *National Report on Biochemical Indicators of Diet and Nutrition in the U.S. Population*.

National Environmental Public Health Tracking Program

The CDC's public health tracking program helps to track environmental hazards and the diseases they may cause, coordinating and integrating local, state and Federal health agencies' collection of critical health and environmental data. The web-based National Environmental Public Health Tracking Network launched this past summer. CEHN strongly supports this program.

Data on children's "real world" exposure and disease are critically needed. Since children spend hours every day in school and child care, we urge you to direct the Tracking Program to include grants for pilot methods for tracking children's health in schools and child care settings.

To date, 24 grantees have received funds from the CDC for health tracking networks that will feed into the national network. Health officials in *all* states need integrated health and environmental data so that they can protect the public's health. We urge the Committee to provide \$50 million for the Health Tracking Program in FY 11, enabling CDC to fund up to 13 new grantees.

National Institute of Environmental Health Sciences (NIEHS)

The NIEHS is the leading institute conducting research to understand how the environment influences the development and progression of human disease. Thus it is a vital institution in our efforts to understand how to protect children, whether it is identifying and understanding the impact of substances that are endocrine disruptors or understanding childhood exposures that may not affect health until decades later. The NIEHS is poised to generate many new exciting discoveries about the impact of environmental factors on human health.

NIEHS's National Toxicology Program is the leading federal program studying the toxicity of environmental agents in our environment; a major focus of this program is endocrine disrupting chemicals, substances that mimic or suppress hormones which have been implicated in numerous adverse health effects.

NIEHS is studying the health effects of global climate change. The Institute has taken the lead among Federal agencies to develop a comprehensive research plan to respond to the significant consequences that climate change is expected to have on human health.

The Network asks you to provide \$779.4 million for NIEHS in FY11.

Children's Environmental Health Research Centers of Excellence

The Children's Environmental Health Research Centers, jointly funded by the U.S. EPA and NIEHS, play a key role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets (unchanged over more than 10 years), these centers generate valuable research. A unique aspect of these Centers is the requirement that each Center actively involves its local community in a collaborative partnership, leading both to community-based participatory research projects and to the translation of research findings into child-protective programs and policies.

The scientific output of these centers has been outstanding. For example, findings from four Centers clearly showed that prenatal exposure to a widely-used pesticide affected developmental outcomes at birth and early childhood. This was important information to EPA's policy makers in their consideration of this pesticide.

The Congress recognized this last year, when it supported increased funding, resulting in the upcoming addition of a child care component and additional research. These goals call for a continued effort, yet the Administration's FY11 budget proposal did not continue this funding. We strongly urge that the Committee reinstate these funds and direct NIEHS to sustain this effort.

Unfortunately, almost all of the existing 12 centers are currently operating on no-cost extensions and only five of the existing centers are to be renewed. If centers are shuttered, we will lose access to valuable populations such as children with asthma or children growing up with pesticide exposure in farm communities. We will lose the ability to learn about issues like early puberty concerns, exposures in school settings, and pre-adolescent and adolescent outcomes.

National Children's Study (NCS)

The National Children's Study is examining the effects of environmental influences on the health and development of more than 100,000 children across the United States, following them from before birth until age 21. This landmark longitudinal cohort study -- involving a consortium of agencies -- will form the basis of child health guidance, interventions, and policy for generations to come.

We urge the Committee to assure stable support for this study, recognizing that the necessary components of the study are resource intensive. It is vital, however, that this study proceed and also guarantee that scientists, clinicians, and policy makers will have a complete archive of the study's exposure measurements. This study may be the only means that we will have to understand the links between exposures and the health and development of children and to identify the antecedents for a healthy adulthood.

A study of this scope is calls for the participation of multiple agencies. We urge the Committee to assure that the NCS remains a collaborative study that retains on its original environmental focus. While the NCS is housed at NIH, it must be a multi-agency study and it must be responsive to its mission and to the lead agencies, in and out of NIH.

The Network also asks the Committee to direct that protocols are in place for measuring exposures in child care and school settings. It is critically important to understand how school and child care exposures differ from home exposures very early in the NCS.

Pediatric Environmental Health Specialty Units (PEHSU)

Funded by the Agency for Toxic Substances and Disease Registry and the U.S. EPA, the PEHSUs form a valuable resource network, with a center in each of the U.S. Federal regions. PEHSU professionals provide medical consultation to health care professionals on a wide range of environmental health issues. PEHSUs also provide information and resources to school, child care, health and medical, and community groups. PEHSUs assist policymakers by providing data and background on local or regional environmental health issues and implications for specific populations or areas. These centers, all based in universities, have done tremendous

work on very limited budgets. We urge the Committee to fully fund ATSDR's portion of this program's FY 11 budget of \$1.8 million.

Environmental Health in Schools

Each school day, about 54 million children and nearly 7 million adults —20% of the total U.S. population—spend a full week inside schools. Unfortunately, many of the nation's school facilities are shoddy or even "sick" buildings whose environmental conditions harm children's health and undermine attendance, achievement, and productivity.

No agency is authorized to intervene to protect children from environmental hazards in schools. Thus, every day we require our children to spend hours in an environment where they and their parents have no options, alternatives or recourse if the environment is not healthy.

Thus, the Network urges the Committee to provide full funding for the aspects of the Clean, Green and Healthy Schools Initiative in its jurisdiction. Agencies need adequate resources to assure their participation in the vital cross-agency work of this initiative.

A formal partnership between HHS, DoEd, and EPA to coordinate their pediatric environmental health efforts would leverage resources and be beneficial for children's health and research. Providing resources for the newly re-vitalized Interagency Task Force on Children's Environmental Health would support such a partnership.

Environmental Health in Child Care Settings

60% of preschoolers — 13 million children —are in child care. This youngest and most vulnerable population can enter care as early as six weeks of age and be in care for more than 40 hours per week. Yet little is known about the environmental health status of these centers. The Network is working to correct these gaps.

We urge the Committee to bring the child care environment into the Clean, Green and Healthy Schools Initiative by providing additional resources and direction focused on this important environment.

We ask the Committee to direct the HHS Assistant Secretary for Children and Families to report on the Administration for Children and Families (ACF) activities that protect children from environmental hazards in child care settings, especially in the Office of Head Start.

In conclusion, investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures, an outcome we can all support. That is why the Network asks you to give priority to these programs.

Thank you for the opportunity to testify on these critical issues.

Cynthia F. Bearer, M.D., Ph.D. – Curriculum Vitae

| INSTITUTION AND LOCATION | DEGREE (if applicable) | YEAR(s) | FIELD OF STUDY |
|-------------------------------------|---------------------------|---------|-------------------|
| Smith College, MA | B.A. | 1972 | Mathematics |
| Case Western Reserve University, OH | Ph.D. | 1977 | Smith College, MA |
| Johns Hopkins University, MD | M.D. | 1982 | Medicine |
| Baylor College of Medicine, TX | Postdoc | 1977-78 | Cell Biology |
| University of Texas, Houston, TX | Postdoc | 1978-79 | Pharmacology |

1982-1984 Resident, Pediatrics, The Johns Hopkins Hospital, Baltimore, MD
 1984-1986 Fellow, Joint Program of Neonatology, Harvard Medical School, MA
 1986-1987 Fellow, Division of Newborn Medicine, Washington University School of Medicine, MO; Instructor in Pediatrics, Washington University School of Medicine, MO
 1990-1991 Postgraduate training, Occupational and Environmental Health, UCSF, CA
 1990-1992 Assistant Clinical Professor, Department of Growth and Development, UCSF, CA
 1992-1994 Associate Professor, Department of Pediatrics, NEOUCOM, OH
 1994-2001 Assistant Professor, Departments of Pediatrics and Neurosciences, CWRU, OH
 2000-2002 Co-Director, Neonatology Fellowship Training Program, CWRU, OH
 2001-2008 Associate Professor, Depts of Pediatrics, Neurosciences and EHS, CWRU, OH
 2002-2008 Director, Neonatology Fellowship Training Program, CWRU, OH
 2003 Award of tenure, CWRU, OH
 2006-2008 Associate Director, Medical Scientist Training Program, CWRU, OH
 2008 Professor, Depts of Pediatrics, Neurosciences and EHS, CWRU, OH
 2008-Present Mary Gray Cobey Professor of Neonatology with tenure, University of Maryland
 2008-Present Chief, Division of Neonatology, University of Maryland School of Medicine.

Other Experience and Professional Memberships including Federal Advisory Committees:

1990-Present American Academy of Pediatrics; 1993-Present Research Society on Alcoholism and Fetal Alcohol Syndrome Disorder Study Group; 1993-Present Board member, Children's Environmental Health Network; 1995-1999 American Academy of Pediatrics, Committee on Environmental Health; 1995-Present Society for Pediatric Research; 1996-Present Children's Health Initiative Workgroup, ATSDR; 1996-Present American Academy of Pediatrics, Section on Perinatal Pediatrics; 1996-Present Food Quality Protection Act/Science Review Board, U.S. EPA; 1997 External Scientific Advisory Board: Fetal Alcohol Syndrome, NIAAA/NIH; 1998 NIAAA Special Emphasis Panel; 1999 NIH Special Emphasis Panel ZAA1 BB(3); 1998-2001 Science Advisory Board, Environmental Health Subcommittee, U.S. EPA; 1999-2003 Consultant, Advisory Group to the Director, NCEH, CDC; 1999-Present Perinatal Research Society; 2000-Present Society for Neuroscience; 2001-Present Editorial Board, Neurotoxicology; 2001-2003 Review Panel, NTP for the Evaluation of Risks to Human Reproduction, NIEHS; 2001-2006 Committee on Evaluation of Children's Health, NAS/NRC/IOM; 2002 Grant Peer Review Panel, Children's Vulnerability to Toxic Substances in the Environment (2-D1), U.S. EPA; 2002-2003 Temporary member, ALTX-3 Study Section; 2003-2006 Permanent member, NAL Study Section; 2003-2005 Board of Directors, Physicians for Social Responsibility; 2004 Ad hoc reviewer, scientific review group EHS (T32 & T35), EHS-LKB-TG; 2004-Present Ad hoc reviewer, AA-1 Study section; 2007 Ad hoc expert, NIAAA/NIH Extramural Advisory Board; 2007 NIAAA/NIH Special Emphasis Panel ZAA1 CC(11); 2008 Chair, National Children's Study Biological and Environmental Sample Repository Meeting, review of proposals, NIH/NICHD; 2008 Neuroscience Review Subcommittee, AA-4, NIH/NIAAA (K08); 2008 Chair, Biorepository Meeting, review of proposals, NIH/NICHD; 2009 Ad hoc reviewer, ZRG1 IFCN-A (58) R Challenge Grants; 2009 Ad hoc Reviewer, ZAA1 CC (03) R Effect of Alcohol on Glia; 2009 Ad hoc Reviewer, Children's Environmental Health Center grants; 2009 Ad hoc Reviewer, Developmental Brain Disorders Study Section; 2009 Chair of the Board, Children's Environmental Health Network; 2010 ZRG1-ETTN A (14) SBIR/STTR Study Section.
 Peer reviewed articles (44), patents (1), book chapters (11).

Cynthia F. Bearer, M.D., Ph.D. – Curriculum Vitae

| INSTITUTION AND LOCATION | DEGREE (if applicable) | YEAR(S) | FIELD OF STUDY |
|-------------------------------------|---------------------------|---------|-------------------|
| Smith College, MA | B. A. | 1972 | Mathematics |
| Case Western Reserve University, OH | Ph.D. | 1977 | Smith College, MA |
| Johns Hopkins University, MD | M.D. | 1982 | Medicine |
| Baylor College of Medicine, TX | Postdoc | 1977-78 | Cell Biology |
| University of Texas, Houston, TX | Postdoc | 1978-79 | Pharmacology |

1982-1984 Resident, Pediatrics, The Johns Hopkins Hospital, Baltimore, MD
 1984-1986 Fellow, Joint Program of Neonatology, Harvard Medical School, MA
 1986-1987 Fellow, Division of Newborn Medicine, Washington University School of Medicine, MO; Instructor in Pediatrics, Washington University School of Medicine, MO
 1990-1991 Postgraduate training, Occupational and Environmental Health, UCSF, CA
 1990-1992 Assistant Clinical Professor, Department of Growth and Development, UCSF, CA
 1992-1994 Associate Professor, Department of Pediatrics, NEOUCOM, OH
 1994-2001 Assistant Professor, Departments of Pediatrics and Neurosciences, CWRU, OH
 2000-2002 Co-Director, Neonatology Fellowship Training Program, CWRU, OH
 2001-2008 Associate Professor, Depts of Pediatrics, Neurosciences and EHS, CWRU, OH
 2002-2008 Director, Neonatology Fellowship Training Program, CWRU, OH
 2003 Award of tenure, CWRU, OH
 2006-2008 Associate Director, Medical Scientist Training Program, CWRU, OH
 2008 Professor, Depts of Pediatrics, Neurosciences and EHS, CWRU, OH
 2008-Present Mary Gray Cobey Professor of Neonatology with tenure, University of Maryland
 2008-Present Chief, Division of Neonatology, University of Maryland School of Medicine.

Other Experience and Professional Memberships including Federal Advisory Committees:

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Peer reviewed articles (44), patents (1), book chapters (11).

Mr. OBEY. Thank you. We appreciate your comments.
Next, Leonardo Trasande, Children's Environmental Health Center.

WEDNESDAY, MAY 12, 2010.

NATIONAL CHILDREN'S STUDY

WITNESS

LEONARDO TRASANDE, M.D., CO-DIRECTOR, CHILDREN'S ENVIRONMENTAL HEALTH CENTER, MT. SINAI MEDICAL CENTER

Dr. TRASANDE. Chairman Obey, Members of the Subcommittee, thank you for the opportunity to update you on ongoing progress at the National Children's Study, our Nation's opportunity to address the preventable and environmental causes of the epidemic of chronic conditions that affect children today.

I co-direct the Children's Environmental Health Center at the Mt. Sinai School of Medicine, the Nation's first academic policy center devoted to the protection of children against environmental threats to health, and serve as the location principal investigator for Queens, New York, one of seven locations where the National Children's Study launched in early 2009.

The National Children's Study is a prospective study that will follow 100,000 American children, a nationally representative sample of all children born in the United States, from conception to age 21, and was mandated by Congress through the Children's Health Act of 2000. The study will gather an unprecedented volume of high quality data on how environmental factors acting either alone or in combination with genetics affect the health of infants and children, examining a wide range of environmental factors from air, water and dust, to what children eat and how often they see a doctor.

The study will help develop prevention strategies and cures for a wide range of childhood diseases. The National Children's study will employ the latest tools in molecular epidemiology and will incorporate state of the art analyses of gene-environment interactions.

Congress has already laid a firm foundation for the National Children's Study. Between 2000 and 2009, Congress invested more than \$580,000,000 to design the study and begin building the nationwide network for its implementation. Seven vanguard centers and a coordinating center were designed in 2005 to test the necessary research guidelines with plans to expand the program to 41 States and 105 communities nationwide.

Findings in these study centers have suggested that further refinements are necessary to ensure the most cost-effective investment in implementing the study, and generating policy-relevant findings for decades to come. The study has recently been expanded to 30 additional locations where approaches to recruitment can be more fully optimized.

A formative research program will generate new knowledge that will inform redesign of key questionnaires and other data collection approaches in response to important concerns that were raised by

the National Academy of Sciences regarding the original vanguard protocol.

The tough job of designing and organizing is nearly complete. Funding for the study this year will permit researchers to begin achieving the results that will make fundamental improvements in the health of America's children. To abandon the study at this point would mean foregoing all of that dedication, all of that incredible effort, and all of that logistical preparation.

The National Children's Study will yield benefits that far outweigh its cost. Six of the diseases that are the focus of the study cost America over \$642 billion each year. If the study were to produce even a 1 percent reduction in the cost of these diseases, it would receive \$6,400,000,000 annually, 50 times the average yearly cost of the study itself.

The Framingham Heart Study upon which the National Children's Study is modeled, is the prototype for longitudinal medical studies and contributed powerfully to the 42 percent reduction in mortality rates from cardiovascular disease that were achieved in our Country over the past five decades.

Funding for the study will require a commitment of \$194,000,000. These funds will be used to begin enrolling children in to the study. They will enable the NIH to continue establishing the 105 study sites around the Country. We do not need to wait 21 years for benefits to materialize from the study. Valuable information will become available in a few years time, as soon as the first babies in the study are born.

The National Children's Study will provide a blueprint for the prevention of disease and for the enhancement of health of America's children today and in the future. It will be our legacy to the generations yet unborn.

Thank you for the opportunity to speak before you today.

[Written statement by Leonardo Trasande, M.D. follows:]

Testimony of Leonardo Trasande, MD, MPP
Co-Director, Children's Environmental Health Center
Department of Preventive Medicine
Mount Sinai School of Medicine

before the Labor, Health and Human Services Subcommittee
Committee on Appropriations
U.S. House of Representatives
12 May 2010

**The National Children's Study: Our Hope for Improving the Health of the Next
Generation of America's Children**

The National Children's Study is a prospective multi-year epidemiological study that will follow 100,000 American children, a nationally representative sample of all children born in the United States, from conception to age 21. The study will assess and evaluate the environmental exposures these children experience in the womb, in their homes, in their schools and in their communities. It will seek associations between environmental exposures and disease in children. The diseases of interest include all those listed above. The principal goal of the Study is to identify the preventable environmental causes of pediatric disease and to translate those findings into preventive action and improved health care.

The National Children's Study was mandated by Congress through the Children's Health Act of 2000. The lead federal agency principally responsible for the Study is the National Institute of Child Health and Human Development. Other participating agencies include the National Institute of Environmental Health Sciences, the Environmental Protection Agency, the Centers for Disease Control and Prevention and the Department of Education. By working with pregnant women and couples, the Study will gather an unprecedented volume of high-quality data on how environmental factors acting either alone, or in combination with genetic factors, affect the health of infants and children. Examining a wide range of environmental factors – from air, water, and dust to what children eat and how often they see a doctor – the Study will help develop prevention strategies and cures for a wide range of childhood diseases. By collecting data nationwide the study can test theories and generate hypotheses that will inform biomedical research and the care of young patients for years to come. Simply put, this seminal effort will provide the foundation for children's healthcare in the 21st Century.

Six aspects of the architecture of the National Children's Study make it a uniquely powerful tool for protecting the health of America's children:

1. The National Children's Study is prospective in its design. The great strength of the prospective study design is that it permits unbiased assessment of children's exposures in real time as they actually occur, months or years before the onset of disease or dysfunction. Most previous studies have been forced to rely on inherently inaccurate retrospective reconstructions of past exposures in children who were already affected with disease. The prospective design obviates the need for recall. It is especially crucial for studies that require assessments of fetal and infant exposures, because these early exposures are typically very transitory and will be missed unless they are captured as they occur.

2. The National Children's Study will employ the very latest tools of molecular epidemiology. Molecular epidemiology is a cutting-edge approach to population studies that incorporates highly specific biological markers of exposure, of individual susceptibility and of the precursor states of disease. Especially when it is embedded in a prospective study, molecular epidemiology is an extremely powerful instrument for assessing interactions between exposures and disease at the level of the individual child.

3. The National Children's Study will incorporate state-of-the-art analyses of gene-environment interactions. Recognition is now widespread that gene-environment interactions are powerful determinants of disease in children. These interactions between the human genome and the environment start early in life, affect the health of our children, and set the stage for adult disorders. The heroic work of decoding the human genome has shown that only about 10-20% of disease in children is purely the result of genetic inheritance. The rest is the consequence of

interplay between environmental exposures and genetically determined variations in individual susceptibility. Moreover, genetic inheritance by itself cannot account for the sharp recent increases that we have seen in incidence of pediatric disease.

4. The National Children's Study will examine a nationally representative sample of American children. Because the 100,000 children to be enrolled in the Study will be statistically representative of all babies born in the United States during the five years of recruitment, findings from the Study can be directly extrapolated to the entire American population. We will not need to contend with enrollment that is skewed by geography, by socioeconomic status, by the occurrence of disease or by other factors that could blunt our ability to assess the links between environment and disease.

5. Environmental analyses in the National Children's Study will be conducted in close collaboration with the Centers for Disease Control and Prevention. The CDC laboratories in Atlanta are the premier laboratories in this nation and the world for environmental analysis. The testing done at CDC is the best available worldwide, making results of environmental analyses unimpeachable.

6. Samples collected in the National Children's Study will be stored securely and will be available for analysis in the future. New tests and new hypotheses will undoubtedly arise in the years ahead. Previously unsuspected connections will be discovered between the environment, the human genome and disease in children. The stored specimens so painstakingly collected in the National Children's Study will be available for these future analyses.

Congress has already laid a firm foundation for the National Children's Study. Between 2000 and 2009, the Congress invested more than \$580 million to design the study and begin building the nationwide network necessary for its implementation. Seven Vanguard Centers and a Coordinating Center were designated in 2005 at sites across the nation – in Pennsylvania, New York, North Carolina, Wisconsin, Minnesota, South Dakota, Utah and California – to test the necessary research guidelines – with plans to expand the program to 41 states and 105 communities nationwide. Findings in these Study Centers have suggested that further refinements are necessary to ensure the most cost-effective investment in implementing the Study and generating policy relevant findings for decades to come. The Study has recently been expanded to thirty additional locations where approaches to recruitment can be more fully optimized. A formative research program will generate new knowledge that will inform redesign of key questionnaires and other data collection approaches, in response to important concerns that were raised by the National Academy of Sciences regarding the original Vanguard protocol.

The tough job of designing and organizing is nearly complete. Funding for the Study this year will permit researchers to begin achieving the results that will make fundamental improvements in the health of America's children. To abandon the Study at this point would mean forgoing all of that dedication, all of that incredible effort, and all of the logistical preparation.

The National Children's Study will yield benefits that far outweigh its cost. It will be an extraordinarily worthwhile investment for our nation, and it can be justified even in a time of fiscal stress such as we face today. Six of the diseases that are the focus of the Study (obesity, injury, asthma, diabetes, autism and schizophrenia) cost America at least \$642 billion each year. If the Study were to produce even a 1% reduction in the cost of these diseases, it would save \$6.4

billion annually, 50 times the average yearly costs of the Study itself. But in actuality, the benefits of the National Children's study will likely be far greater than a mere 1% reduction in the incidence of disease in children. The Framingham Heart Study, upon which the National Children's Study is modeled, is the prototype for longitudinal medical studies and the benefits that it has yielded have been enormous. The Framingham Study was launched in 1948, at a time when rates of heart disease and stroke in American men were skyrocketing, and the causes of those increases were poorly understood. The Framingham Study used path-breaking methods to identify risk factors for heart disease. It identified cigarette smoking, hypertension, diabetes, elevated cholesterol and elevated triglyceride levels as powerful risk factors for cardiovascular disease. These findings contributed powerfully to the 42% reduction in mortality rates from cardiovascular disease that we have achieved in this country over the past 5 decades.

The data from Framingham have saved millions of lives – and billions of dollars in health care costs. The National Children's Study, which will focus on multiple childhood disorders, could be even more valuable. We do not need to wait 21 years for benefits to materialize from the National Children's Study. Valuable information will become available in a few years' time, as soon as the first babies in the Study are born.

Consider, for example, data on premature births. The rate of U.S. premature births in 2003 was 12.3%, far higher than the 7% rate in most western European countries. Hospital costs associated with a premature birth average \$79,000, over 50 times more than the average \$1,500 cost for a term birth. Just a 5% reduction in rates of prematurity would cut hospital costs by \$1.6 billion annually. Within just two years, that savings would match the full cost of the Study.

The Study enjoys a broad group of supporters, including The American Academy of Pediatrics; Easter Seals; the March of Dimes; the National Hispanic Medical Association; the National Association of County and City Health Officials; the National Rural Health Association; the Association of Women's Health, Obstetric and Neonatal Nurses; United Cerebral Palsy; the Spina Bifida Association of America; and the United States Conference of Catholic Bishops, just to name a few. This broad and diverse group recognizes the overwhelming benefits this Study will produce for America's children.

Congress first authorized the National Children's Study in 2000, and has appropriated \$584.8 million since then to design the Study, pursue preparatory research, and designate Study Centers that will be piloting the Study in thirty-seven locations by the end of the calendar year. Products in the form of thoughtful reviews of Study design (including reviews on the hypotheses relating to the epidemic of childhood obesity) have already been published, and are submitted appended to this written testimony for the record. More are already being developed for peer review, and will advance the state of the science of children's environmental health.

Funding for the Study this year requires a commitment of \$194 million. These funds will be used to begin enrolling children in the study. They will enable the NIH to continue establishing the 105 study sites around the country. We urge Congress to fully fund the National Children's Study. It is an investment in our children – and in America's future. The National Children's Study will give our nation the ability to understand the causes of chronic disease that cause so much suffering and death in our children. It will give us the information that we need on the environmental risk factors and the gene-environment interactions that are responsible for rising rates of morbidity and mortality. It will provide a blueprint for the prevention of disease and for

the enhancement of the health in America's children today and in the future. It will be our legacy to the generations yet unborn.

Mr. OBEY. Thank you.

Mr. REHBERG. May I ask how old you are? You look really young.

Dr. TRASANDE. That is kind. I am 36. [Laughter.]

Mr. RYAN. Hey, Rehberg, quit picking on young people, okay? We don't appreciate that. We have a caucus going over here. [Laughter.]

Mr. REHBERG. Don't you wish you had that resume. [Laughter.]

Mr. OBEY. Next, David Meltzer, American Red Cross.

WEDNESDAY, MAY 12, 2010.

**CENTERS FOR DISEASE CONTROL AND PREVENTION,
GLOBAL IMMUNIZATION**

WITNESS

DAVID MELTZER, SENIOR VICE PRESIDENT FOR INTERNATIONAL SERVICES, AMERICAN RED CROSS

Mr. MELTZER. Thank you, Chairman Obey and Members of the Subcommittee. The American Red Cross appreciates the opportunity to submit testimony in support of the measles control activities of the U.S. Centers for Disease Control and Prevention.

We recognize the leadership that Congress has shown in funding CDC for these essential activities and we sincerely hope that the Congress will continue to support the CDC during this critical period in measles control.

In 2001, CDC, along with the American Red Cross, the United Nations Foundation, the World Health Organization, and UNICEF founded the Measles Initiative, a partnership committed to reducing measles deaths globally.

The current UN goal is to reduce measles deaths by 90 percent by 2010 compared to 2000 estimates. Working towards this goal, the Measles Initiative has achieved spectacular results by supporting the vaccination of more than 700 million children around the world. Largely due to the Measles Initiative, global measles mortality dropped by 78 percent from an estimated 733,000 deaths in the year 2000 to 164,000 deaths in 2008. During this same period in Africa, measles deaths fell by 92 percent, from 371,000 to just 28,000.

Working closely with host governments, the Measles Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$720,000,000 and provided technical support in more than 60 developing countries on vaccination campaigns, surveillance, and improving routine immunization services.

From 2000 to 2008, an estimated 4.3 million deaths were averted as a result of these accelerated measles control activities at a donor cost of \$184 per death averted. This makes measles mortality reduction one of the most cost-effective public health interventions.

Nearly all the measles vaccination campaigns have been able to reach more than 90 percent of their target populations. By the end of 2008, all WHO regions, with the exception of Southeast Asia, achieved the 2010 goal two years ahead of target. The extraordinary reduction in global measles deaths contributed an estimated

25 percent of the progress to date toward Millennium Development Goal Number 4, which is reducing under age 5 child mortality.

However, at the height of global achievements in measles control, a sharp decline in commitment threatens to erase the gains of the last decade and permit a global measles resurgence. The Measles Initiative presently faces a funding shortfall of an estimated \$47,000,000 for 2011. The American Red Cross, which has to date contributed \$141,000,000 to the Initiative, currently faces financial challenges that reduce my organization's foreseeable funding capacity.

Current funding gaps have led to delays in mass campaigns, which have resulted in outbreaks and regrettably deaths. Sufficient funding must be secured for measles control activities in order to achieve the 2010 goal and to avoid a measles resurgence.

Since fiscal year 2001, Congress has provided \$43,600,000 annually in funding to CDC for global measles control activities. These funds were used towards the purchase of 415 million doses of measles vaccine for use in large scale measles vaccination campaigns in more than 60 countries in Africa and Asia, and for the provision of technical support to the Ministries of Health in those countries.

Your commitment has brought us unprecedented success in reducing measles mortality around the world. The CDC support made possible by the Congressional funding was essential to achievement of the sharp reduction in measles deaths in just eight years. In fiscal year 2010, Congress has appropriated \$51,900,000 to fund CDC for global measles control activities. The American Red Cross thanks Congress for the increase in financial support from past years. We respectfully request level funding for fiscal year 2011 for CDC's measles control activities to prevent a global resurgence of measles and a loss of progress toward Millennium Development Goal Number 4.

Thank you for the opportunity to submit testimony.

[Written statement by David Meltzer follows:]

**TESTIMONY OF
DAVID MELTZER, SENIOR VICE PRESIDENT, INTERNATIONAL SERVICES
THE AMERICAN NATIONAL RED CROSS**

**AND ON BEHALF OF
THE HONORABLE TIMOTHY E. WIRTH, PRESIDENT,
UNITED NATIONS FOUNDATION**

**IN SUPPORT OF FUNDING FOR THE CENTERS FOR DISEASE CONTROL AND
PREVENTION (CDC)**

**APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION AND RELATED AGENCIES**

**UNITED STATES HOUSE OF REPRESENTATIVES
May 12, 2010**

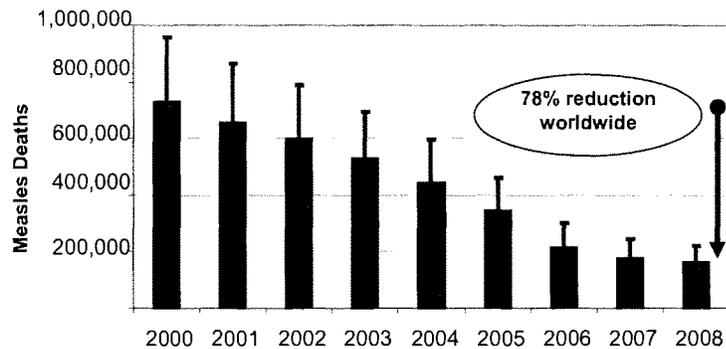
Chairman David Obey, Ranking Member Todd Tiahrt, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. We sincerely hope that Congress will continue to support the CDC during this critical period in measles control.

In 2001, CDC – along with the American Red Cross, the United Nations Foundation, the World Health Organization, and UNICEF – founded the Measles Initiative, a partnership committed to reducing measles deaths globally. The current UN goal is to reduce measles deaths by 90% by 2010 compared to 2000 estimates. The Measles Initiative is committed to reaching this goal by providing technical and financial support to governments and communities worldwide.

The Measles Initiative has achieved “spectacular”¹ results by supporting the vaccination of more than 700 million children. Largely due to the Measles Initiative, global measles mortality dropped 78%, from an estimated 733,000 deaths in 2000 to 164,000 in 2008. During this same period, measles deaths in Africa fell by 92%, from 371,000 to 28,000.

¹ The Lancet, Volume 8, page 13 (January 2008).

Figure 1: Estimated Number of Global Measles Deaths, 2000-2008



Working closely with host governments, the Measles Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$720 million and provided technical support in more than 60 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2008, an estimated 4.3 million measles deaths were averted as a result of these accelerated measles control activities at a donor cost of \$184/death averted, making measles mortality reduction one of the most cost-effective public health interventions.

Nearly all the measles vaccination campaigns have been able to reach more than 90% of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children, and “integrating” the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, Vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine (reduces malnutrition), and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. The scale of these distributions is immense. For example, more than 40 million ITNs were distributed in vaccination campaigns in the last few years. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children’s health from a single campaign.

By the end of 2008 all WHO regions, with the exception of one (South East Asia), achieved the 2010 goal two years ahead of target. The extraordinary reduction in global measles deaths contributed an estimated 25% of the progress to date toward Millennium Development Goal #4 (reducing under-five child mortality). However, at the height of global achievements in measles control, a sharp decline in commitments threatens to erase the gains of the last decade and a global measles resurgence is likely. If mass immunization campaigns are not continued, an

estimated 1.7 million measles-related deaths could occur between 2010-13, with more than half a million deaths in 2013 alone.

To achieve the 2010 goal and avoid a resurgence of measles the following actions are required:

- Accelerating activities, both campaigns and further efforts to improve routine measles coverage, in India since it is the greatest contributor to the global burden of measles.
- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90% of infants are vaccinated against measles through routine health services before their first birthday as well as conducting timely, high quality mass immunization campaigns.
- Securing sufficient funding for measles-control activities both globally and nationally. The Measles Initiative faces a funding shortfall of an estimated US \$47 million for 2011. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at global level to support measles elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 90%.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles cases in other countries, U.S. children are also being protected from the disease. Measles can cause severe complications and death. A resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths. Since then, measles control measures in the United States have been strengthened and endemic transmission of measles cases have been eliminated here since 2000. However, importations of measles cases into this country continue to occur each year. In 2008, several measles outbreaks in the United States, all linked to importation of the virus from overseas, led to the largest number of U.S. measles cases since 1996. These cases resulted in dozens of hospitalizations and the costs of response to the outbreaks were substantial, both in terms of the costs to public health departments and in terms of productivity losses among people with measles, parents of sick children, and people exposed to measles cases.

The Role of CDC in Global Measles Mortality Reduction

Since FY 2001, Congress has provided approximately \$43.6 million annually in funding to CDC for global measles control activities. These funds were used toward the purchase of approximately 415 million doses of measles vaccine for use in large-scale measles vaccination campaigns in more than 60 countries in Africa and Asia, and for the provision of technical support to Ministries of Health in those countries. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;

- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles Initiative, there is no doubt that CDC's support – made possible by the funding appropriated by Congress – was essential in helping achieve the sharp reduction in measles deaths in just eight years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles Initiative is fortunate in having a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In FY 2010, Congress has appropriated approximately \$51.9 million to fund CDC for global measles control activities. The American Red Cross and the United Nations Foundation thank Congress for the increase in financial support from past years. We respectfully request level funding for FY 2011 for CDC's measles control activities to prevent a global resurgence of measles and a loss of progress toward Millennium Development Goal #4.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.

David B. Meltzer

David B. Meltzer joined the American Red Cross in 2005 after spending the previous 16 years at Intelsat, the world's largest satellite Communications Company.

At the American Red Cross, Mr. Meltzer is directly responsible for the international activities of the organization, including health programs in over thirty countries, the \$580 million Tsunami Recovery Program, and disaster response activities throughout the world. He is also responsible for international policy issues and strategy.

Prior to joining the American Red Cross, Mr. Meltzer was the General Counsel and Executive Vice President for Regulatory Affairs of Intelsat and responsible for all legal and regulatory activities of the multinational company doing business in over 200 countries and territories. Before becoming the General Counsel, Mr. Meltzer held a number of positions at Intelsat including leading the successful effort to privatize the former intergovernmental organization with 145 member states, as well as leading the department responsible for procuring billions of dollars of telecommunications satellites, launch vehicles, and related goods and services.

Before joining Intelsat, Mr. Meltzer was engaged in the private practice of law in the area of international trade and government contracts. He also worked at the World Bank for the World Bank Legal Department.

Mr. Meltzer earned his B.A. in International Relations from the University of Pennsylvania, and received a J.D. from George Washington University.

Mr. Meltzer, who is married with three children, lives in Bethesda, Maryland

Mr. OBEY. Thank you.
Next, James Lacy, Rotary International.

WEDNESDAY, MAY 12, 2010.

CENTERS FOR DISEASE CONTROL

WITNESS

PAST PRESIDENT AND CHAIR JAMES LACY, POLIO ERADICATION ADVOCACY TASK FORCE, ROTARY INTERNATIONAL

Mr. LACY. Thank you very much, Chairman Obey and Members of the Subcommittee. On behalf of 1.2 million Rotarians in more than 170 countries around the world, we thank you for your tremendous commitment to polio eradication globally.

Thanks to your leadership in appropriating funds, progress toward a polio-free world continues on a positive course. Only four countries have never stopped polio transmission: Afghanistan, Pakistan, India and Nigeria.

The number of polio cases has fallen more than 99 percent from an estimated 350,000 cases in 1988 to only 1,606 cases in 2009. This year to date, the number of polio cases globally is 84 compared to 383 at the same point in 2009. India went seven weeks without reporting any case of the wild polio virus. This is the first such lull in polio transmission since records have been kept. Transmission of polio in India is now focused in only 107 blocks in two states, a geographic area representing only 2 percent of that country.

Due to increased ownership from national and state governments and religious and traditional leaders in Nigeria, the only polio endemic country in Africa, has reported only two cases of polio for 2010. By this point in 2009, polio had paralyzed 236 children. Twelve of the 20 reinfected countries in 2009 and 2010 have not reported a case of polio in the last six months.

In March and April, 2010, countries throughout West and Central Africa took part in a preplanned synchronized immunization campaign. Political interest in the campaigns were extensive. Six heads of state and one First Lady launched the campaigns. This included the critical new involvement of the President of Chad, who declared war against polio.

In sum, the prospects for polio eradication are better than ever in terms of the low level of polio incidence and the commitment to polio eradication in the polio endemic and outbreak countries.

Lack of funds to conduct necessary activities may now pose the biggest threat. We have yet to identify sources of support for approximately half the U.S. \$2,600,000,000 needed between now and the end of 2012 to achieve the goal of stopping all outbreaks and interrupting transmission of the wild polio virus.

Rotary is committed to doing whatever it takes to ensure we seize the opportunity to conquer polio once and for all. Rotarians have already contributed more than \$900,000,000 in this effort, plus thousands of man hours and are more than halfway to our current fundraising goal of \$200,000,000.

The leadership of the United States remains essential and Rotary International urges you continued support toward the shared

goal of a polio-free world. For fiscal year 2011, we respectfully request that you include \$102,000,000 of level funding for the targeted polio eradication efforts of the Centers for Disease Control and Prevention.

The funds we are seeking will allow CDC to continue intense supplementary immunization activities in Asia and improve the quantity and quality of immunization campaigns in Africa to ensure we meet the goal of interrupting transmission of wild polio in these regions as quickly as possible.

These funds will also help maintain certification standard disease surveillance, which is essential to protecting against and responding to outbreaks. Failure to achieve success would have significant humanitarian and economic consequences.

Within the next decade, hundreds of thousands of children would again be paralyzed for life by this disease. Billions of dollars would have to be spent on outbreak response activities, rehabilitation, and treatment costs, and the associated loss to economic productivity.

Success, on the other hand, will ensure that the significant investment made by the United States, Rotary International and many other countries and entities is protected in perpetuity.

Thank you very much for your continued support, and we thank you especially, Mr. Chairman, for your support through the years, and thank you also for you also for the opportunity to give this testimony.

Thank you.

[Written statement by James Lacy follows:]

Mr. James Lacy
Past President and Chair of the Polio Eradication Advocacy Task Force
Cookeville, Tennessee

May 12, 2010
2:00 PM to 4:30 PM

Rotary International

The Global Polio Eradication Initiative is an unprecedented model of cooperation among national governments (led by the United States), civil society (led by Rotary International) and UN agencies to work together to eliminate the crippling disease of polio from the world. The prospects for polio eradication are better than ever in terms of the low level of polio incidence and commitment to polio eradication in the polio endemic and outbreak countries.

For Fiscal Year 2011, we respectfully request that the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee include \$102 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention (CDC). These funds will allow CDC to continue intense supplementary immunization activities in Asia and improve the quality of immunization campaigns in Africa to ensure we meet the goal of interrupting transmission of wild polio in these regions as quickly as possible. These funds will also help maintain certification standard disease surveillance, which is essential to protecting against and responding to outbreaks.

Chairman Obey, Representative Tiahrt, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The Global Polio Eradication Initiative is an unprecedented model of cooperation among national governments, civil society and UN agencies to work together to reach the most vulnerable through a safe, cost-effective public health intervention, and one which is increasingly being combined with opportunistic, complementary interventions such as the distribution of life-saving vitamin A drops, oral rehydration therapy, zinc supplements, and even something as simple as the distribution of soap. The goal of a polio free world is within our grasp because polio eradication strategies work even in the most challenging environments and circumstances.

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

I would like to take this opportunity to thank you, Chairman Obey, Representative Tiahrt, and members of the Subcommittee for your tremendous commitment to this effort. Thanks to your leadership in appropriating funds, progress toward a polio-free world continues.

- Only 4 countries (Nigeria, India, Pakistan and Afghanistan) are polio-endemic – the lowest number in history.
- The number of polio cases has fallen from an estimated 350,000 in 1988 to slightly more than 1,600 in 2009 – a more than 99% decline in reported cases.
- As of 16 April, 2010, the number of polio cases globally is 75% less than at the same point in 2010.
- In Nigeria, the only polio endemic country in Africa, cases of type 1 polio declined by 90% in 2009. This dramatic improvement is a direct result of increased ownership from national and state governments, and religious and traditional leaders. As of 16 April 2010, Nigeria was reporting only 1 case of polio. By this point in 2009, polio had paralyzed 171 children.
- Transmission of polio in India has been reduced to the point that it is now focused in 107 blocks - a geographic area that comprises about 2% of the country. India now has one remaining genetic chain of type-1 transmission - down from nine four years ago.
- Bivalent oral polio vaccine was introduced at the end of 2009 as a tool that effectively targets both of the remaining strains of polio, thus facilitating planning and logistics.
- Twelve of the twenty re-infected countries in 2009 & 2010 have not reported a case of polio in the last 4 months.
- From 6-8 March, 2010, 16 countries took part in a pre-planned synchronized immunization campaign across Africa. Political interest in the campaigns was extensive - six Heads of State and one First Lady launched the campaigns. This included the critical new involvement of the President of Chad, who declared "war against polio".

In summary, significant operational progress was made in 2009. The progress already made in 2010 shows the Global Polio Eradication Initiative is well positioned to make additional significant gains, given sufficient resources to conduct vital polio immunization and surveillance activities. Rotary, as a spearheading partner of the Global Polio Eradication Initiative, will continue to pursue aggressive progress as outlined in the Strategic Plan for 2010-12.

The ongoing support of donor countries is essential to assure the necessary human and financial resources are made available to polio-endemic countries to take advantage of the window of

opportunity to forever rid the world of polio. Access to children is needed, particularly in conflict-affected areas such as Afghanistan and its shared border with Pakistan. Polio-free countries must maintain high levels of routine polio immunization and surveillance. The continued leadership of the United States is essential to ensure we meet these challenges.

THE ROLE OF ROTARY INTERNATIONAL

Since 1985, Rotary International, a global association of more than 30,000 Rotary clubs, with a membership of over 1.2 million business and professional leaders in more than 200 countries, has been committed to battling this crippling disease. In the United States today there are more than 7,700 Rotary clubs with over 375,000 members. Rotary International stands hand-in-hand with the United States Government and governments around the world to fight polio through local volunteer support of National Immunization Days, raising awareness about polio eradication, and providing financial support for the initiative.

Rotarians have reaffirmed their own commitment to achieve polio eradication and have already raised more than half of the fund are currently in the midst of their third fundraising campaign, "Rotary's US\$200 Million Challenge," in response to an extraordinary challenge grant of US\$355 million global for polio eradication from the Bill & Melinda Gates Foundation. By the time the world is certified polio free, Rotary's contribution to global polio eradication will exceed US\$1.2 billion – second only to that of the United States Government. These funds have been allocated for polio vaccine, operational costs, laboratory surveillance, cold chain, training and social mobilization in 122 countries.

In addition to providing financial support, Rotarians in other donor countries are working to ensure that those countries, particularly G8 member states, continue their vital financial support. Meanwhile, our Rotarian leaders in the remaining polio-affected countries work to ensure political commitment from the community level all the way to the head of state level. We are doing our best to ensure that we finish the job into which so much has been invested.

Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Birth Defects Foundation, the American Academy of Pediatrics, the Task Force for Child Survival and Development, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in expressing appreciation to you for your staunch support of the Global Polio Eradication Initiative.

THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's support of CDC's polio eradication activities. The investment in this global effort has helped to make the United States the leader among donor nations in the drive to eradicate this crippling disease. Due to Congress's unwavering support, in FY2010 CDC was able to:

- Support the international assignment of more than 358 long- and short-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies, and 29 technical staff on direct assignment to WHO and UNICEF to assist polio-endemic countries.

- Provide \$46.2 million to UNICEF for approximately 259 million doses of polio vaccine and \$5.7 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.
- Work with UNICEF to take advantage of the World Bank buy-down mechanism by providing \$6 million to leverage the purchase of 298.4 million doses of oral polio vaccine in Pakistan.
- Provide more than \$29 million to WHO for surveillance, technical staff and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveillance is critical to determine where polio cases continue to occur. Effective surveillance can save resources by eliminating the need for extensive immunization campaigns if it is determined that polio circulation is limited to a specific locale.
- Train virologists from around the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories serve as a global reference center and training facility.
- Provide the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.
- Serve as the primary technical support agency to WHO on scientific and programmatic research regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination worldwide following global certification of polio eradication.

The CDC also supports global polio eradication by participating in technical advisory groups, EPI manager and other key meetings. The CDC also published eight updates on progress toward polio eradication in the Morbidity and Mortality Weekly Report (MMWR) and planned the following operational research projects:

Southeast Asia

- Participated in/coordinated the 5-arm clinical trial of IPV and OPV in Moradabad, India, showing high seroprevalence against WPV1 upon enrollment at 6-9 months of age.
- Designed AFP seroprevalence investigations in West Uttar Pradesh, also showing high seroprevalence against WPV1 at 6-9 months of age.
- Designed, planned and supervised expanded surveillance in India.
- Participated in AFP surveillance reviews in northern India.
- Participated in an EPI/Surveillance Review in Indonesia.
- Assisted in the preparation of Kosi area/Indian high-risk district polio eradication intensification plan.

Eastern Mediterranean area and Africa

- Completed the investigation of cases following three importations into Angola from India. This included conducting a case-control study indicating apparent risk factors of traveling adults in the households.
- Planned, trained, deployed and supervised extended STOP teams (eSTOP) (larger, well-experienced teams for lower level oversight of SIA planning and implementation) in South Sudan and Nigeria.
- Participated in outbreak response planning and implementation following importations in West Africa originating from Nigeria, following importations in central Africa originating from Nigeria/Angola and importations in the countries of the Horn of Africa originating from Sudan.
 - Eight missions to seven countries of West Africa and one to a country of central Africa
 - 13 missions to four countries of the Horn of Africa
- Participated in an assessment of Integrated Disease Surveillance in South Africa
- Participated in a mid-level management training in Nigeria
- Organized a comprehensive evaluation of SIA implementation in Nigeria, with piloting of data collection at the end of 2009, for implementation in early 2010.

FISCAL YEAR 2011 BUDGET REQUEST

For Fiscal Year 2011, we respectfully request that you include \$102 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention. The funds we are seeking will allow CDC to continue intense supplementary immunization activities in Asia and improve the quality of immunization campaigns in Africa to interrupt transmission of polio in these regions as quickly as possible. These funds will also help maintain certification standard surveillance. This will ensure that we protect the substantial investment we have made to protect the children of the world from this crippling disease by supporting the necessary eradication activities to eliminate polio in its final strongholds—in South Asia and sub-Saharan Africa.

The United States' commitment to polio eradication has stimulated other countries to increase their support. Other countries that have followed America's lead and made special grants for the global Polio Eradication Initiative include the United Kingdom (\$897.89 million), Japan (\$376.6 million), Germany (\$378.77 million), and Canada (\$272.25 million). Since 2002, the members of the G8 have committed to provide sufficient resources to eradicate polio. G8 member states, many of which were already leading donors to the Polio Eradication Initiative, have encouraged other donors to provide support, and have emphasized the importance of polio eradication when meeting with leaders of polio-endemic countries. As a result, the base of donor nations that have contributed to the Global Polio Eradication Initiative has expanded to include Spain, Sweden, Saudi Arabia, and even contributions from United Arab Emirates, Kuwait, Hungary, and Turkey.

Endemic nations are also providing funds to support polio eradication activities. It is noteworthy that India has provided US\$692 million in funding for polio eradication activities there since 2003, Nigeria has provided approximately US\$61.75 million, and Pakistan has provided US\$50 million.

BENEFITS OF POLIO ERADICATION

Since 1988, over 5 million people who would otherwise have been paralyzed will be walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to investigate cases of acute flaccid paralysis and manage massive immunization programs. Cold chain, transport and communications systems for immunization have been strengthened.

Increased political and financial support for childhood immunization has many documented long-term benefits. Polio eradication is helping countries to develop public health and disease surveillance systems useful in the control of other vaccine-preventable infectious diseases. Already all 47 countries of the Americas are free of indigenous measles, due in part to improvements in the public health infrastructure implemented during the war on polio. The disease surveillance system--the network of 145 laboratories and trained personnel established during the Polio Eradication Initiative--is now being used to track measles, rubella, yellow fever, meningitis, and other deadly infectious diseases. The AFP surveillance system and global laboratory network that supports it will continue to support the surveillance of other diseases long after polio has been eradicated.

NIDs for polio have been used as an opportunity to give children essential vitamin A, which, like polio, is administered orally, saving the lives of at least 1.25 million children since 1988. The campaign to eliminate polio from communities has led to an increased public awareness of the benefits of immunization, creating a "culture of immunization" and resulting in increased usage of primary health care and higher immunization rates for other vaccines. It has improved public health communications and taught nations important lessons about vaccine storage and distribution, and the logistics of organizing nation-wide health programs. Additionally, the unprecedented cooperation between the public and private sectors serves as a model for other public health initiatives.

The justification for further financing to complete the job of polio eradication is sound. Failure to achieve success would have significant humanitarian and economic consequences. Within the next decade, hundreds of thousands of children would again be paralyzed for life by the disease. Billions of dollars would have to be spent on outbreak response activities, rehabilitation and treatment costs, and the associated loss of economic productivity. Success, on the other hand, will ensure that the significant investment made by the US, Rotary International, and many other countries and entities, is protected in perpetuity.

The strong resolve of the remaining polio affected countries combined with the continued leadership of the United States and other global donors will ensure that we seize the opportunity to banish the crippling polio virus to the history books. The lessons learned from the shared victory of governments, UN agencies, and civil society entities like Rotary International will leave a lasting legacy for future public health and development initiatives.



Lacy, James, Cookeville, Tennessee, USA

Member, International PolioPlus Committee, 1996-1997, 2000-2003, 2004-2010
 Chair, Polio Eradication Advocacy Task Force for the United States, 2006-2010
 Vice-Chair, Polio Eradication Advocacy Task Force, 2001-2003, 2004-2006
 Trustee Chair, The Rotary Foundation, 2003-2004
 Trustee Vice-Chair, The Rotary Foundation, 2002-2003
 Trustee, The Rotary Foundation, 1994-1997, 2000-2002
 Member, Polio Eradication Advocacy Task Force, 2000-2001
 President, Rotary International, 1998-1999
 President's Advisory Committee, 1997-1998
 Director, Rotary International 1988-1990

James Lacy is a past President of Rotary International. Projects to address problems facing the children of the world were emphasized during his tenure as president.

A member of the Rotary club of Cookeville, Tennessee since 1964, Mr. Lacy has also served Rotary International as district governor; International Assembly instructor, delegate to the Council on Legislation, assistant moderator, and moderator; committee member, vice chair, and chair; task force member and vice chair; Rotary information counselor; Foundation trustee and chair; and director.

Past vice-chair of the Polio Eradication Advocacy Task Force and current chair of the Polio Eradication Advocacy Task Force for the United States, he has received The Rotary Foundation's Citation for Meritorious Service and its Distinguished Service Award.

James Lacy currently serves as a consultant to Gilliam Candy Brands Inc., a national confection manufacturer that he recently sold. He has been active in local government and has served in the Tennessee General Assembly.

In recognition of Mr. Lacy's continuous community involvement Lincoln Memorial University in Harrogate, Tennessee, conferred upon him the degree of Honorary Doctor of Public Service. He has also received an Honorary Doctor of Economics degree from Kangnung National University in Korea.

Mr. OBEY. Thank you very much.
Thank you all for testifying. That is it for the day, just in time.
The Committee stands adjourned.

WRITTEN STATEMENTS FROM
RELATED AGENCIES AND OTHER
INTERESTED INDIVIDUALS OR
ORGANIZATIONS



FOR THE RECORD

**WRITTEN TESTIMONY IN SUPPORT OF INCREASED
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)**

BY

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**TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES OF THE COMMITTEE ON
APPROPRIATIONS**

U.S. HOUSE OF REPRESENTATIVES

APRIL 8, 2010

THE ARR AND CIBR REQUEST FISCAL YEAR (FY) 2011 NIH FUNDING AT \$35 BILLION, WHICH REFLECTS A \$3 BILLION INCREASE OVER THE PRESIDENT'S PROPOSED FUNDING LEVEL OF \$32 BILLION

Thank you for providing the Academy of Radiology Research and the Coalition for Imaging and Bioengineering Research with the opportunity to submit this testimony to the Labor, Health and Human Services, Education, and Related Agencies Subcommittee of the Committee on Appropriations for consideration as it works on fiscal year 2011 funding.

The imaging research community commends Congress for \$10.4 billion in NIH funding in the American Recovery and Reinvestment Act (ARRA), as well as FY2009 and FY2010 funding increases that enabled NIH to keep pace with biomedical inflation after six previous years of flat funding that resulted in a 14 percent loss of purchasing power. FY2011 NIH funding at \$35 billion enables it to meet the expanded capacity for research — as demonstrated by the significant number of high-quality grant applications submitted in response to ARRA opportunities — and to adequately address unmet needs, especially for programs of special promise that could reap substantial downstream benefits, as identified by NIH Director Francis Collins, M.D., Ph.D. in his top five priorities. As President Obama has repeatedly stated, including at a visit to the NIH in September 2009, biomedical research has the potential to reduce healthcare costs, increase productivity, and ensure the global competitiveness of the United States of America.

Funding at \$35 billion, which reflects NIH's net funding levels in both FY2009 and FY2010, ensures it can maintain the number of multi-year investigator-initiated research grants, the foundation of our nation's biomedical research enterprise. Although much has been accomplished, biomedical research still has an enormous amount of ground to cover before discovery is turned into health for all Americans.

THE ARR AND CIBR REQUEST INCREASED NIH FUNDING TOWARDS A MULTI-FACETED, NATIONAL IMAGING RESEARCH INITIATIVE TO ENSURE THAT IONIZING RADIATION IS USED ONLY WHEN MEDICALLY NECESSARY AND APPROPRIATE

Over the past forty years, imaging technology has revolutionized the way in which we diagnose and treat illness. By using magnetic resonance imaging (MRI), computed tomography (CT) fluoroscopy and nuclear medicine procedures such as positron emission tomography (PET), clinicians have been able to improve survival and decrease morbidity by identifying disease earlier and treating it less invasively, often eliminating more dangerous and costly surgical procedures. Furthermore, imaging technology reduces hospital length of stay and decreases recovery time.

Conversely, along with their unmistakable contributions to patient care, these improved imaging technologies have yielded a new set of challenges for the medical community, patients, policymakers and taxpayers. The number of imaging procedures has increased dramatically, imaging costs have soared, duplicative studies are too common and concern is growing about the amount of ionizing radiation that patients receive from diagnostic and clinical imaging.

The increasing use of ionizing radiation for diagnostic imaging warrants greater scrutiny of population-based and cumulative individual risks. The need to minimize risk without compromising diagnostic imaging quality is highly desirable, particularly in vulnerable populations such as children and women of reproductive capacity.

However, sufficient resources must be devoted to meet this need. At present, while five per cent of health care expenditures are devoted to imaging, only 1% of biomedical research funds are targeted to imaging research. We must narrow this disparity by directing NIH to immediately begin a multi-institute sponsored strategic plan for the future of biomedical imaging. The plan would develop a 'basic' and 'translational' research road map to guide investments in comparative effectiveness research, electronic decision support and dosage risk analysis to reduce national imaging costs and radiation exposure, while improving patient outcomes.

By investing in a strategic imaging research initiative, NIH can expeditiously deliver the tools necessary to curb over utilization of imaging and reduce risks to patients through improved decision support and more careful management of radiation dosages actually received by patients. Health information technology (HIT) legislation, ARRA funding, and the recently enacted health care reform legislation have begun the process of reordering the health care system to incentivize better outcomes rather than simply paying for more procedures. At present, however, we lack the informational tools to distinguish the two. Only an immediate strategic plan for imaging research can deliver what is necessary in this vital component of our health care system.

To that end, the ARR and CIBR recommend an increase of at least \$50 million for these purposes to the NIH, the Agency for Healthcare Research and Quality (AHRQ), and the Centers for Medicare and Medicaid Services (CMS). This funding would go towards a multi-faceted, national initiative to ensure that ionizing radiation is used only when medically necessary and appropriate.

The initiative will consist of a number of components. It will encourage or require improvements to diagnostic imaging equipment and software; allow lower doses for each exam through the utilization of patient-specific and exam-specific information; increase transparency of the expected and actual doses; introduce failsafe mechanisms to minimize or prevent errors; and track dosage data that would be available through electronic health records.

Informatics efforts would be implemented to harvest radiation exposure data from healthcare providers and place them in data registries to provide patient access to necessary data. The use of computerized physician order entry (CPOE) would be encouraged or mandated to incorporate evidence-based practice guidelines for appropriate use. And self-referral opportunities, which may result in overutilization of advanced imaging, would be limited or eliminated.

Funding would also go towards research that would answer key radiation safety questions, such as optimizing image quality and comparative effectiveness research, and the training of medical professionals to manage and reduce dose and adopt best practices. In addition, a standardized

approach to benchmark radiation doses associated with medical imaging examinations, as well as accreditation requirements, would be adopted.

Much more can and should be done to reduce and manage ionizing radiation exposure attendant to diagnostic imaging, and much progress can be made without sacrificing the crucial benefits that medical imaging delivers to patients across the disease spectrum.

THE ARR AND CIBR REQUEST THAT CONGRESS INCREASE FUNDING FOR NIH INSTITUTES BENEFITING FROM IMAGING RESEARCH

Imaging affects all diseases and medical conditions. It is essential to accurately and efficiently diagnose disease. As technology advances, imaging will play an even more prominent role in disease detection. Therefore, an investment towards imaging research is critical. With that said, the ARR and CIBR ask that Congress increase funds for the NIH institutes which benefit from basic and translational imaging research. These institutes include the National Institute of Biomedical Imaging and Bioengineering (NIBIB), the National Cancer Institute (NCI), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Aging (NIA), the National Institute of Mental Health (NIMH), and the National Institute on Drug Abuse (NIDA).

This additional funding will support job creation and research and development in biomedical imaging and bioengineering in a variety of ways. These include support for summer research experiences in innovative technology research for students and teachers in NIBIB-funded laboratories. One signature project focused on HIT research to improve patient outcome and health care efficiency.

In seeking to translate biomedical discovery into better health, these institutes will continue to encourage research that teams biomedical engineers and physical scientists with clinical and basic biological scientists to translate basic science. Interdisciplinary research has developed new imaging techniques as well as improved image processing. These advanced techniques are now being applied in a clinical setting to expedite disease detection and improve understanding of disease processes. This emphasis on interdisciplinary research will reinvigorate biomedical research.

ABOUT ARR AND CIBR

ARR is a 501(c)6 non-profit alliance comprised of professional imaging societies.

CIBR is a 501(c)6 non-profit partnership of academic research departments, scientific societies, patient advocacy organizations, and imaging equipment manufacturers leading the education and advocacy efforts for imaging research.



Written Testimony to the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee Regarding Fiscal Year 2011 Funding for Congenital Heart Disease Programs

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The Adult Congenital Heart Association (ACHA) is pleased that the recently enacted "Patient Protection and Affordable Care Act" includes provisions to enhance and expand the infrastructure to track the epidemiology of congenital heart disease (CHD) and to conduct and support research on causation, including genetic causes; long-term outcomes in individuals with congenital heart disease; diagnosis, treatment, and prevention; studies using longitudinal data and retrospective analysis to identify effective treatments and outcomes; and identifying barriers to life-long care for individuals with congenital heart disease. The Adult Congenital Heart Association, along with coalition partners Mended Little Hearts and Children's Heart Foundation, stand ready to work with the Subcommittee and Members of Congress to advance these policies.

Congenital heart defects are the most common birth defect in the United States and are a leading cause of child mortality. The success of childhood cardiac intervention has created a new chronic disease – CHD. Those who receive successful intervention will need life-long special cardiac care and face high rates of heart failure, rhythm disorders, stroke and sudden cardiac death. Thanks to the increase in survival, the CHD population is rising by 5 percent a year. There are about 800,000 children and 1 million adults in the United States now living with CHD.

Despite the prevalence and seriousness of the disease, data collection and research are limited. In 2004, the National Heart, Lung and Blood Institute (NHLBI) convened a working group on congenital heart disease, which recommended developing a research network to conduct clinical research and establishing a national database of patients.

Federal funding support for CHD surveillance through CDC and research through NHLBI will help prevent premature death and disability in this rapidly-growing and severely underserved population.

FY 2011 Written Testimony for the Labor, Health and Human Services,
and Education Subcommittee of the House Appropriations Committee

By Ronald Johnson, Deputy Executive Director, AIDS Action Council

I am pleased to submit this testimony to the Members of this committee on the importance of increased funding for the Fiscal Year (FY) 2011 domestic HIV/AIDS portfolio. Since 1984, AIDS Action Council, through its member organizations and the greater HIV/AIDS and public health communities, has worked to enhance HIV prevention programs, research protocols, and care and treatment services at the community, state and federal level. AIDS Action Council represents many AIDS service organizations located in the nation's HIV epicenters, local health departments, smaller service providers, faith-based organizations, substance abuse treatment centers, and education and advocacy organizations from all over the country. AIDS Action Council's goals are to ensure effective, evidence-based HIV care, treatment, and prevention services; to encourage the continuing pursuit of a cure and a vaccine for HIV infection; and to support the development of a public health system which ensures that its services are available to all those in need. On behalf of AIDS Action Council's diverse membership I bring your attention to issues impacting funding for FY 2011.

Nearly 30 years since it was first identified, the HIV/AIDS epidemic in the United States is characterized by needless mortality, inadequate access to care, persistent levels of new infection, and stark racial inequalities. Despite the good news of improved treatments, which have made it possible for people with HIV disease to lead longer and healthier lives, stark realities remain. Consider that in the United States...

- Every year, 55,000 people are newly infected with HIV in the United States – **one new infection every 9 ½ minutes**. According to the Centers for Disease Control and Prevention (CDC) the HIV infection rate has not fallen in 15 years and the new incidence figure represent a 40% increase from previous estimates.
- Over a million people are estimated to be living with HIV or AIDS; nearly **half of people living with HIV/AIDS are not in care**.
- Of those people living with HIV/AIDS **21% are unaware of their HIV status**.
- CDC estimates in **2007, 14,561 people died** from AIDS related causes.
- African Americans represent **13% of the United States population but nearly 50% of all newly reported HIV infections**.
- Hispanics/Latinos represent **13% of the United States population but account for 18% of newly reported cases of HIV**.
- **The percentage of newly reported HIV/AIDS cases in the U.S. among women tripled from 8% to 27% between 1985 and 2007**.
- AIDS is the **leading cause of death among black women aged 25-34**
- HIV is the **#1 health care risk for gay men and men who have sex with men, especially in communities of color**.
- More than **half of all newly diagnosed individuals are identified with full blown AIDS in less than 12 months of their initial HIV positive diagnosis**.
- There is neither a cure nor a vaccine for HIV and current treatments do not work for everyone.

The federal government's commitment to funding prevention, research, and care and treatment for those living with HIV is critical. We would be unable to respond to this epidemic without the federal government's increased commitment to funding domestic HIV programs. However, the federal government is not doing enough. The unsatisfactory outcomes from our country's response to AIDS have serious human and economic costs. The federal government commitment to HIV domestic funding is even more important this year as we see then number of states lowering their state funding contributions due to the economic realities state budgets are facing as they work to balance their budgets. We need more HIV prevention, more treatment and care and more research if we are ever to slow and eventually reverse the HIV epidemic.

It is AIDS Action Council's expectation that the Congress, through the good work of this subcommittee, will recognize and address the true funding needs of the programs in the HIV/AIDS portfolio. HIV is a 100% preventable disease that can be lessened with a focused, concentrated effort and increased funding. The HIV community has come together under the umbrella of the AIDS Budget and Appropriations Coalition with the community funding request for the HIV/AIDS domestic portfolio for FY 2011.

The Centers for Disease Control and Prevention estimate that approximately thirteen percent of all HIV cases and approximately 60 percent of all hepatitis C cases in the United States are directly or indirectly related to intravenous drug use. One of the most important ways to reduce these epidemics is through the use of syringe exchange. More than eight federal studies along with numerous scientific peer reviewed papers published over 15 years have conclusively established that syringe exchange programs reduce the incidence of HIV among people who inject drugs and their sexual partners. Such studies have all concluded that syringe exchange does not increase drug abuse. Instead, syringe exchange programs connect people who use drugs to health care services including addiction treatment, HIV and viral hepatitis prevention services and testing, counseling, education, and support.

The removal of the ban on federal funding for syringe exchange was an important step to enable local and state jurisdictions to respond effectively to the twin HIV and hepatitis epidemics. **AIDS Action Council and the HIV community recommend that the Committee sustain the compromise language allowing local jurisdictions to decide if they want to use federal funds to establish or carry out a program of distributing sterile syringes to reduce the transmission of blood borne pathogens, including the human immunodeficiency virus (HIV) and viral hepatitis.**

According to CDC estimates contained in the agency's 2007 HIV/AIDS Surveillance Report, since the beginning of the epidemic there have been 1,030,832 AIDS cases reported with a total of 562,793 deaths in the United States. As noted above, the CDC estimates that between 1.1 and 1.2 million people are living with HIV/AIDS and that 250,000 -350,000 people are unaware of their HIV status and could unknowingly transmit the virus to another person. We are appreciative that last year in Fiscal Year 2010 the committee saw fit to increase the HIV prevention and surveillance line by \$36 million. Prior to last year funding had remained essentially flat for more than eight years. As a result, grants to states and local communities have significantly decreased just as new reported infections have increased to an estimated 56,300 in 2006, according to a CDC report released in August 2008. **Therefore, AIDS Action Council,**

the HIV community, and the CDC in their budget justification before Congress September 2008, estimates that the CDC HIV Prevention and Surveillance programs will need \$1.5 billion, an increase of \$878 million, in FY 2010 to address the true unmet needs of preventing HIV in the United States.

We request an increase of \$20 million, for a total of \$60.2 million, for the Division of Adolescent and School Health's HIV Prevention Education at the CDC. We need to invest in programs that provide all of our young people with complete, accurate, and age-appropriate sex education that helps them reduce their risk of HIV, other STDs, and unintended pregnancy. In these tight budget times, we are pleased that the President's FY11 budget increased funding for the new teen pregnancy prevention initiative. However, by focusing the funding on teen pregnancy prevention, and not including the equally important health issues of STDs and HIV, we think the Administration has missed an opportunity to provide true, comprehensive sex education that promotes healthy behaviors and relationships for all young people, including LGBT youth. So many negative health outcomes are inter-related and we need to strategically and systemically provide youth with the information and services they need to make responsible decisions about their sexual health. **We request that the teen pregnancy prevention initiative be broadened to address HIV and other STDs, in addition to the prevention of unintended teen pregnancy, and fund it at least at the President's requested level of \$133.7 million.** We are pleased that the President's budget has once again included zero funding for failed abstinence-only-until-marriage programs and we encourage our colleagues not to include funding for these ineffective programs.

Now in its twentieth year, The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, administered by the Health Resources and Services Administration (HRSA) and funded by this subcommittee, provides services to more than 529,000, people living with and affected by HIV throughout the United States and its territories. It is the single largest source of federal funding solely focused on the delivery of HIV services; it provides the framework for our national response to the HIV epidemic. CARE Act programs have been critical to reducing the impact of the domestic HIV epidemic. Yet in recent years, CARE Act funding has not kept pace with the epidemic and has decreased through across-the-board rescissions. It is important to remember that CARE Act programs are designed to compliment each other. It is necessary that all parts of the CARE Act receive substantial increased funding to ensure the success of the total program. **AIDS Action Council and the HIV/AIDS community estimate that the entire Ryan White CARE Act portfolio needs \$3,101.5 million in FY 2011, an increase of \$810.8 million** to address the true needs of the hundreds of thousands of people living with HIV who are uninsured, underinsured, or who lack financial resource for health care.

Part A of The Ryan White CARE Act provides physician visits, laboratory services, case management, home-based and hospice care, and substance abuse and mental health services. Under the most recent reauthorization these services are even more dedicated towards funding core medical services and to ensuring the ability of patients to adhere to treatment. These services are critical to ensuring patients have access to, and can effectively utilize, life-saving therapies. **AIDS Action Council along with the HIV/AIDS community recommends funding Part A at \$905 million, an increase of \$225.9 million.**

Part B of the CARE Act ensures a foundation for HIV related health care services in each state and territory, including the critically important AIDS Drug Assistance Program (ADAP). Part B

base grants (excluding ADAP) received a decrease of \$28.5 million in FY 2009. **AIDS Action Council along with the HIV/AIDS community recommends funding for Part B base grants at \$474.7 million, an increase of \$55.9 million.**

The AIDS Drug Assistance Program (ADAP) provides medications for the treatment of individuals with HIV who do not have access to Medicaid or other health insurance. According to the 2009 National ADAP Monitoring Project, ADAP provided medications to approximately 183,299 clients in FY 2007, including 36,354 new clients. **AIDS Action Council along with the HIV/AIDS community recommends \$1,205.1 million, an increase of \$370.1 million, for ADAP for FY 2011.** This “community need” number is derived from a pharmacoeconomic model to estimate the amount of funding needed to treat ADAP eligible individuals in upcoming federal and state fiscal years. The need number represents the amount of new funding required to allow state ADAPs to provide a minimum clinical standard formulary of HIV/AIDS medications to ADAP clients under the current eligibility rules for each state. ADAPs across the country have experienced significant challenges due to the state budget accounts; this program needs particular attention due to many state cuts.

Part C of the Ryan White CARE Act awards grants to community-based clinics and medical centers, hospitals, public health departments, and universities in 22 states and the District of Columbia under the Early Intervention Services program. These grants are targeted toward new and emerging sub-populations impacted by the HIV epidemic. Part C funds are particularly needed in rural areas where the availability of HIV care and treatment is still relatively new. Urban areas continue to require Part C funds as emerging populations as grantees struggle to meet the needs of previously identified HIV positive populations. **AIDS Action Council, along with the HIV/AIDS community, requests \$337.9 million, an increase of \$131 million, for Part C.**

Part D of the Ryan White CARE Act awards grants under the Comprehensive Family Services Program to provide comprehensive care for HIV positive women, infants, children, and youth, as well as their affected families. These grants fund the planning of services that provide comprehensive HIV care and treatment and the strengthening of the safety net for HIV positive individuals and their families. **AIDS Action Council and the HIV/AIDS community request \$84.8 million, an increase of \$7 million, for Part D.**

Under Part F, the AIDS Education and Training Centers (AETCs) is the training arm of the Ryan White CARE Act; they train the healthcare providers, including the doctors, advanced practice nurses, physicians’ assistants, nurses, oral health professionals, and pharmacists. The role of the AETCs is invaluable in ensuring that such education is available to healthcare providers who are being asked to treat the increasing numbers of HIV positive patients who depend on them for care. Additionally, the AETCs have been tasked with providing training on Hepatitis B and C to CARE Act grantees and to ensure inclusion of culturally competent programs for and about HIV and Native Americans and Alaska Natives. However little funding has been added for additional materials, training of staff, or programs in recent years. **AIDS Action Council and the HIV/AIDS community request \$50 million, a \$15.2 million increase, for this program.** Also under Part F, Dental care is another crucial part of the spectrum of services needed by people living with HIV disease. Oral health problems are often one of the first manifestations of HIV

disease. Unfortunately oral health is one of the first aspects of health care to be neglected by those who cannot afford, or do not have access to, proper medical care removing an opportunity to catch early infections of HIV. **AIDS Action Council and the HIV/AIDS community request \$19 million, a \$5.4 million increase, for this program.** Finally under Part F, rising infections and strapped care systems necessitate the research and development of innovative models of care. The SPNS program is designed for this purpose and must continue to receive sufficient funding.

The Minority AIDS Initiative directly benefits racial and ethnic minority communities with grants to provide technical assistance and infrastructure support and strengthen the capacity of minority community based organizations to deliver high-quality HIV health care and supportive services to historically underserved groups. HIV/AIDS in the U.S. continues to disproportionately affect communities of color. According to the CDC, in 2007 the overall rate of HIV diagnosis (the number of diagnoses per 100,000 population) in the 34 states (that currently report HIV data) was 21.1 per 100,000. The rate for blacks was roughly 8 times the rate for whites (76.7 per 100,000 vs. 9.2 per 100,000). The Minority AIDS Initiative provides services across every service category in the CARE Act and was authorized for inclusion within the CARE Act for the first time in the 2006 CARE Act reauthorization. It additionally funds other programs throughout HHS agencies. **AIDS Action Council and the HIV/AIDS community request a total of \$610 million for the Minority AIDS Initiative.**

Research on preventing, treating and ultimately curing HIV is vital to the domestic and global control of the disease. It is essential that Office of AIDS Research continue its groundbreaking research in both basic and clinical science to develop a preventative vaccine, microbicides, and other scientific, behavioral, and structural HIV prevention interventions. The United States must continue to take the lead in the research and development of new medicines to treat current and future strains of HIV. NIH's Office of AIDS Research is critical in supporting all of these research arenas. Commitment in research will ultimately decrease the care and treatment dollars needed if HIV continues to spread at the current rate. **AIDS Action Council requests that the National Institutes of Health be funded at \$35 billion in FY 2011 and that the AIDS portfolio must be funded at \$3.5 billion a \$400 million increase.**

HIV is a continuing health crisis in the United States. We must continue to work to fully fund our domestic HIV prevention, treatment and care, and research efforts. On behalf of all HIV positive Americans, and those affected by the disease, AIDS Action Council urges you to increase funding in each of these areas of the domestic HIV/AIDS portfolio. Help us save lives by allocating increased funds to address the HIV epidemic in the United States.

Respectfully submitted,
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**Alliance for Aging Research
Testimony on FY 2011 National Institutes of Health Appropriations**

**Submitted to:
House Subcommittee on Labor, Health and Human Services,
Education and Related Agencies**

**Submitted by:
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April 12, 2010

Chairman Obey and members of the Subcommittee, for more than two decades the not-for-profit Alliance for Aging Research has advocated for research to improve the experience of aging for all Americans. Our efforts have included supporting federal funding of aging research by the National Institutes of Health (NIH), through the National Institute on Aging (NIA) and other institutes and centers that work with the NIA on cross-cutting initiatives. To this end, the Alliance appreciates the opportunity to submit testimony highlighting the important role that the NIH plays in facilitating aging research activities and the ever more urgent need for increased appropriations to advance scientific discoveries to keep individuals healthier longer.

The Alliance for Aging Research supports the continuation and expansion of NIH research activities which affect tens of millions of older Americans. The NIA leads national research efforts within the NIH to better understand the aging process and ways to better maintain the health and independence of Americans as they age. Research on healthy aging has never been more critical for so many Americans as the first of the baby boomers will turn 65 in 2011. Presently, there are about 36 million Americans age 65 and older and this group is expected to double in size within the next 25 years. By 2050, an estimated 19.4 million Americans will be over the age of 85. Health care spending in the U.S. is growing, and by 2018 national health care spending is projected to be about \$4.4 trillion and account for 20.3% of GDP, according to Centers for Medicare and Medicaid Services.

Many diseases of aging are expected to become more widespread as the number of older Americans increases. The number of Americans age 65 and older with Alzheimer's disease is projected to more than double by 2030. A recent report in the Journal of Clinical Oncology projected cancer incidence will increase by about 45% from 2010-2030, accounted for largely by cancer diagnoses in older Americans and minorities, and by 2030, people aged 65 and older will represent 70% of all cancer diagnoses in the U.S. Currently, the average 75-year old has three chronic health conditions and takes five prescription medications. Six diseases- heart disease,

stroke, cancer, diabetes, Alzheimer's and Parkinson's diseases – cost the U.S. over \$1 trillion each year. The rising tide of chronic diseases of aging threatens to deluge the U.S. health care system in the coming years.

Late-in-life diseases such as type 2 diabetes, cancer, neurological diseases, heart disease, and osteoporosis are increasingly driving the need for healthcare services in this country. If rapid discoveries are not made now to reduce the prevalence of age-related diseases and conditions like these, the costs associated with caring for the oldest and sickest Americans will place an unmanageable burden on patients, their families, and our health care system. According to a 2005 AHRQ report, up to \$2.5 billion per year could be saved by preventing diabetes-related hospitalizations with appropriate primary care, and much of the savings would come from Medicare and Medicaid. Osteoporosis is estimated to cost the U.S. \$25.3 billion per year by 2025 unless discoveries are made to better treat and prevent the disease. According to an Alzheimer's Association report from 2004, research breakthroughs that slow the onset and progression of Alzheimer's disease could yield annual Medicare savings of \$51 billion by 2015 and \$126 billion by 2025. Research which leads to a better understanding of the aging process and human vulnerability to age-related diseases could help Americans live longer, more productive lives, and help reduce the need for care to manage costly chronic diseases.

In FY 2009, the NIA, which supports a range of genetic, biological, clinical, social and economic research related to aging and the diseases of the elderly, oversaw approximately 1,900 research projects. Through the Division of Aging Biology (DAB), the NIA funds research focused on understanding and exploiting the mechanisms underlying the aging process. Research supported by the DAB program is critically important in that much of it is centered around how changes in function considered to be "normal aging" become risk factors for many age-associated infirmities. Some studies supported by the DAB assess the beneficial effects of reducing caloric intake in animals. Intramural and extramural research is ongoing to test compounds that mimic this process in subjects with the potential to extend the years of disease-free life. Both approaches have produced promising results that may lead to insights into human applications. By capitalizing on these and other successful studies to identify genes that influence longevity, investigators hope to delay the onset of disease and disability associated with human aging in the future.

The NIA has supported grants in recent years to examine public health concerns caused by the rising obesity epidemic. In particular, NIA's Division of Behavioral and Social Science Research funded projects to investigate the role social networks play in influencing an individual's food choices, acceptability of being overweight, and how those networks might be modifiable to slow the spread of obesity; as well as those to explore how the rapid increase in obesity will negatively affect U.S. gains in life expectancy. Investigators supported by the Division of Geriatrics and Clinical Gerontology have focused heavily on the central role exercise plays in improving the health of older adults, reducing health risks associated with diabetes and cardiovascular disease, and lowering the risk of death by increasing an individual's fitness level. Results from studies such as these will not only yield important information for use in the care of the elderly, but also for promoting healthier behavior by the larger U.S. population.

The NIA also participates in collaborations on disease-specific research aimed at preventing, diagnosing, and more effectively treating age-related illnesses. The Alzheimer's Disease Neuroimaging Initiative (ADNI) is a major public-private partnership led by the NIA to evaluate imaging technologies, biological markers, and other tests to improve knowledge surrounding the progression of Alzheimer's disease. ADNI has produced a wealth of data that is accessible to researchers worldwide. It is believed that ADNI findings could lead to shorter and less costly clinical trials for Alzheimer's therapies. Streamlined clinical trials could accelerate the development and approval of more effective AD treatments to the benefit of those who are yet to be diagnosed.

The Diabetes Prevention Program (DPP), a large nationwide clinical study of adults at high risk for diabetes, funded in part by the NIA, showed that lifestyle intervention (intensive training on diet, physical activity and behavior changes with the goal of weight loss) reduced the development of diabetes by 58% over several years. The risk reduction was even greater, 71%, among adults aged 60 years or older. Taking an oral diabetes drug reduced the development of diabetes among participants by 31%, but was less effective in adults over age 45 compared to younger adults. This landmark research study identified effective interventions for adults with pre-diabetes and showed the development of diabetes was not necessarily inevitable but could be slowed or prevented in this group by losing a modest amount of weight through diet and exercise. More recent studies, both completed and ongoing, have further examined DPP data and continue to build on the findings from the diverse group of study participants. The Diabetes Prevention Program Outcomes Study is examining the long term risk reduction effects of the DPP intervention and the clinical course of new-onset diabetes and complications in participants, with attention to differences among minority populations and gender groups. Shedding light on differences between these groups could have wide-reaching implications for millions of Americans at risk for diabetes and may assist in the creation of more effective interventions.

Eighty percent of all the non-profit medical research in the U.S. is funded by the NIH. However, the unfortunate reality is that shrinking budgets have impeded progress. Aging is a field of research whose progress has been hampered by stagnant funding. In part the scarcity of resources has resulted in a decline of the overall success rate for NIH research grant applications. The effect of this has been reluctance on behalf of new investigators to submit truly groundbreaking research proposals for consideration. To operate in this environment the NIA and other institutes involved in aging-related research have not been able to fund increasing numbers of high-quality research grants each year. At its lowest point only one in four research proposals could be funded by the NIH. In recognition of this downward trend, last February President Obama signed into law the American Recovery and Reinvestment Act of 2009 (ARRA), which appropriated \$10.4 billion in funding to the NIH to be used expeditiously in FY 2009 and FY 2010. That March, the NIH budget for FY 2009 was increased 3.2% over FY 2008 to \$30.3 billion. This was a much needed boost across the NIH institutes for critical medical research to benefit Americans, including just over 170 research grants funded by the NIA in ARRA's first year.

Promising areas of research targeted by the NIA to receive ARRA funds include those to identify additional risk factor genes associated with Alzheimer's disease, discovering improved diagnostic tools, possible biomarkers, and therapies. ADNI will receive the most significant amount of stimulus funding to further groundbreaking research that will enable experts to track

changes in living brains as older adults as they transition from normal cognitive aging to the early stages of Alzheimer's disease. The overall impact of this investment will be to increase knowledge of the sequence and timing of events leading up to disease onset and to develop better methods of early detection and monitoring of the disease. Another grant awarded funding through ARRA will develop new technologies, called biosensors, to follow protein folding in cells. Proper protein folding (proteostasis) is important to health. Researchers believe that protein folding is affected by age. If proteins are formed incorrectly, or they misfold normal cell function is disrupted. These problems are thought to cause disease. The biosensors created with ARRA funds will help monitor aging and age-related disease by focusing on patterns of protein folding. ARRA funds have also been awarded to investigators who will study the effects of rapamycin, a compound that mimics caloric restriction, on models of human diseases in mice. Models of Alzheimer's disease, atherosclerosis, cardiovascular disease, Parkinson's disease, kidney disease and cancer will be utilized in this project. The investigators will ultimately seek to determine if the quality of life for the mice has improved and if the age-related diseases have been slowed or reduced over a two-year period.

The ARRA funding begins to make up for flat budgets and unfunded research proposals that have occurred in recent years. However, research at the NIH cannot be sustained and will not flourish in the long term without a steady increase in appropriations which, at minimum, keeps pace with inflation. A slowdown in NIH funding will have a devastating impact on the rate of basic discovery, innovation and the development of interventions which could have major health benefits for the burgeoning population of older Americans. The Alliance for Aging Research supports funding the NIH at \$35 billion in FY 2011 with a minimum of \$1.14 billion in funding for the NIA specifically. This level of support would allow the NIH and the NIA to adequately fund new and existing research projects, accelerating progress toward findings which could prevent, treat, slow the progression or even possibly cure conditions related to aging. With the silver tsunami on the near horizon, an increased investment in NIA's research activities has never been more necessary or had such potential to impact so many Americans.

Mr. Chairman, the Alliance for Aging Research thanks you for the opportunity to outline the challenges posed by the aging population that lie ahead as you consider the FY 2011 appropriations for the NIH and we would be happy to furnish additional information upon request.

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AMERICAN ACADEMY OF NURSE PRACTITIONERS

Incorporated 1965

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**TESTIMONY FOR THE HOUSE APPROPRIATIONS COMMITTEE
REGARDING FUNDING FOR
NURSE PRACTITIONER EDUCATION**

The American Academy of Nurse Practitioners is the full service organization representing over 135,000 nurse practitioners throughout the United States. This testimony speaks to the need for continued and increased federal funding for nurse practitioner educational programs and traineeships for the coming fiscal year.

As the committee knows, nurse practitioners are highly qualified health care providers who have demonstrated their ability and interest in providing primary care to individuals and families in both rural and urban settings, regardless of age, occupation or income. The quality of their care has been well documented over the years. With their advanced preparation, they are able to manage the medical and health problems seen in the primary care and acute care settings in which they work.

Nurse practitioners constitute an effective body of primary care providers that may be utilized at a cost savings in both fee for service and managed care arenas in this country. Savings to the federal government of greater than \$100,000,000 per year in the Medicare program alone are estimated when full utilization of nurse practitioners is implemented. Likewise, managed care data has demonstrated cost savings among patients seen by nurse practitioners when compared to similar patients being cared for by physicians.

Other cost savings that can be realized by the government when nurse practitioners are appropriately utilized, include savings due to reductions in emergency room visits and hospitalizations and savings associated with the treatment of illness in its early stages. Studies in both fee for service and managed care have been conducted that demonstrate cost savings in diagnostic testing, prescribing, hospitalizations and emergency room use when nurse practitioners are utilized to provide primary care to populations of all ages.

Nurse practitioner primary care specialties include family, adult, pediatric, women's health and gerontology. Their services include obtaining medical histories, performing physical examinations, ordering, performing, supervising and interpreting diagnostic tests, diagnosing and treating acute episodic and chronic illnesses including the prescription of medications and other nonpharmacologic treatments, and appropriate referral to other sources of care. In addition, they are skilled in the areas of health promotion and disease prevention which include health education, screening and counseling for patients of all ages.

Nurse practitioners provide primary care in both rural and urban settings, in community health centers, public health clinics, hospitals and hospital outpatient clinics, Indian Health Service and National Health Service Corps sites as well as other freestanding primary care settings. According to data collected by the American Academy of Nurse Practitioners, over 70% of nurse practitioners provide primary care and over 50% of their patients have family incomes in the poverty range.

In order to guarantee the proper preparation of nurse practitioners, assistance in the development of high quality educational programs continues to be needed across the country. The funding for such programs has always been limited, and should always be more. The value and worth of such funding continues to be undisputable.

The sums of money described here are but a drop in the bucket compared to investments made by the federal government to underwrite the cost of preparing other medical professionals. Yet in the face of health care reform and the continued lack of primary care providers in this country, increases in this funding are obviously needed. Without these increases, additional barriers to the effective utilization of the most cost effective primary care providers in our health care system are created.

Likewise, traineeship monies are being utilized by students in all 50 states and the District of Columbia. These monies are of particular importance in the recruitment of nurse practitioners. Current funds fall far short of the mark for assisting in the preparation of these important, cost effective health care providers in the system. These appropriations help to reduce barriers for many students desiring to become nurse practitioners. Surveys of nurse practitioners have shown this investment to be a good one in terms of assisting students who otherwise might not be able to return to school, and in terms of adding providers who care for the rural and urban underserved in this country.

The recommended increase of 10% to the current funding levels in the advanced practice line of Title VIII will only begin to make a dent in meeting the unmet health care needs of today's populations. In light of the current and future needs for primary care providers, it is obvious that increasing appropriations for nurse practitioner education, traineeships and program exploration will be a wise investment.

We thank the members of the Appropriations Committee for their efforts in behalf of nurse practitioners and the patients they serve. We know you recognize the value of our services and the need for utilizing us in the provisions of quality, cost effective health care. It is obvious that we can be part of the solution to the current shortage of health care providers in this country and we are asking for your help to facilitate the process. If there is anything we can do to provide further information or assistance regarding this issue, please feel free to call on us.

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**Written Statement of the
American Academy of Otolaryngology—Head and Neck Surgery
to
Labor, Health and Human Services, Education and Related Agencies
Subcommittee
Committee on Appropriations
United States House of Representatives
April 16, 2010**

On behalf of the world's largest organization representing approximately 11,500 physician specialists who treat the ear, nose, throat, and related structures of the head and neck, the American Academy of Otolaryngology - Head and Neck Surgery (AAO-HNS) appreciates the opportunity to share with the Committee our views on the fiscal year 2011 budget and its impact on important medical research, particularly the work of the National Institute on Deafness and Other Communication Disorders (NIDCD).

The AAO-HNS, while always supportive of more funding for medical research, understands and accepts the budget request for NIDCD in fiscal year 2011 of \$429,007,000. This represents an increase of \$10,174,000, or slightly over 2 percent. This is consistent with other Institutes.

Before we address the specifics of how medical research impacts the AAO-HNS and our specialty, we appreciate the opportunity to inform the Subcommittee about the important services that our members, often referred to as ENT physicians, provide to America's patients.

Diseases and disorders of the ears, nose, throat, head, and neck negatively impact the lives of millions around the world.

The Ears - Hearing loss affects one in ten North Americans. The unique domain of otolaryngologist-head and neck surgeons is the treatment of ear disorders. They are trained in both the medical and surgical treatment of hearing, ear infections, balance disorders, ear noise (tinnitus), nerve pain, and facial and cranial nerve disorders. Otolaryngologist-head and neck surgeons also diagnose and treat congenital (birth) disorders of the outer and inner ear. Conditions that impair hearing and balance function can be as minor as wax buildup or as serious as congenital deafness.

The Nose - About 35 million people develop chronic sinusitis each year, making it one of the most common health complaints in America. Care of the upper respiratory tract, including the nasal cavity and sinuses, is one of the primary skills of otolaryngologist-head and neck surgeons. Management of nasal and sinus disease includes allergies and sense of smell. Ensuring an adequate nasal airway and the normal appearance of the nose are also part of otolaryngologist-head and neck surgeons' expertise. Congestion, allergic rhinitis, nasal trauma, deviated septum, and malignant and infectious conditions of the nose and mouth are just a few of the varied health problems that occur in this region of the body.

The Throat - Communicating (speech and singing), breathing, and swallowing all involve this vital area. Also unique to the skills of otolaryngologist-head and neck surgeons is expertise in managing diseases of the larynx (voice box) and the upper aero-digestive tract or esophagus, including malignant, traumatic, and inflammatory voice and swallowing disorders. Maladies of the throat can be a mere nuisance or a major life-threatening ordeal. Tonsillitis, voice disorders, and even chronic cough and hoarseness all interfere with our ability to communicate. Many of these conditions can be improved or corrected with the care of an ENT physician or head and neck surgeon.

The Head and Neck - Other conditions of the head and neck region involve the important nerves that control sight, smell, hearing, breathing, and the muscles of facial expression and sensation. In the head and neck area, otolaryngologist-head and neck surgeons are trained to treat infectious diseases, both benign and malignant (cancerous) tumors, facial trauma, and deformities of the face, head and neck. They perform both functional and cosmetic plastic and reconstructive surgery.

Many surgical advances are being made in otolaryngology-head and neck surgery. Procedures, such as endoscopic examination and treatment of the nose and throat, tonsillectomy, and facial plastic surgery, are becoming less invasive, and new procedures are being developed to treat serious problems such as cleft palate, sleep apnea, and deafness.

Early detection is critical to preventing fatal outcomes. Cancers of the head and neck, such as oral and laryngeal cancer, can be particularly aggressive. Signs of cancer of the head and neck include changes in the skin, pain, obstruction, prolonged hoarseness, and sudden loss of voice.

Children face many of the same health problems that adults do and others unique to pediatrics. However, symptoms may show themselves differently and treatment methods that work well in adults may not be appropriate for children.

Observed every year in February and sponsored by the AAO-HNS, Kids ENT Health Month is designed to offer parents and caregivers the latest information about the care, diagnosis, and treatment of pediatric ear, nose, and throat disorders. National health statistics reveal that pediatric ear, nose, and throat disorders remain among the primary reasons children visit a physician, with ear infections ranking as the number one reason for an appointment. From earaches to enlarged tonsils, kids can suffer from a variety of ailments that require prompt diagnosis and treatment. Children can also suffer from conditions normally only associated with adults, like chronic acid reflux and sleep apnea, which may require a visit to a pediatric otolaryngologist specialist.

The Importance of Research

Well before the NIDCD was established in 1988, the AAO-HNS recognized the importance of medical research. Established in 1921 with \$27,000 in WWI Liberty Bonds, the Academy's Research Fund began. Yearly, a small portion of each member's dues was marked for the fund, providing it with resources for steady growth. Research grants were given to a variety of projects, and recipients frequently presented their scientific results as papers at our annual meeting. In 1960, the fund was re-established as the Educational Trust Fund and was used to support fellowships in pathology and yearly research awards.

The AAO-HNS and its Foundation's commitment to research has continued to the present day. A series of awards have been established to foster research in a variety of areas. In addition, the Academy was instrumental in advocating for the creation of what eventually became the NIDCD.

Training and Patient Care

Like many other physician specialties, otolaryngologist-head and neck surgeons begin practicing after completing up to 15 years of college and post-graduate training. To qualify for certification by the American Board of Otolaryngology, an applicant must first complete college, medical school (four years), and at least five years of specialty training. Next, the physician must pass the American Board of Otolaryngology examination. In addition, some otolaryngologist-head and neck surgeons pursue a one- or two- year fellowship for more extensive training in one of seven subspecialty areas.

These subspecialty areas are pediatric otolaryngology (children), otology/neurotology (ears, balance, and tinnitus), allergy, facial plastic and reconstructive surgery, head and neck, laryngology (speech, voice and swallowing), and rhinology (nose). Some otolaryngologists limit their practices to one of these seven areas.

AAO-HNS Support for Increased Research Funding

As Congress seeks to improve healthcare and control costs, it is imperative to provide full financial support for medical research. Our members are committed to fighting diseases, developing treatments, and finding cures through medical research. Investments in research can yield significant reductions in future healthcare costs and help improve the quality of life for patients. In fact, according to the National Institute of General Medical Sciences, an investment of \$1 in medical research can result in future savings of over \$80. Clearly, increased funding is a sound investment – today’s discoveries can save the lives of tomorrow’s patients.

Increased funding is necessary to continue our nation’s critical investment in practice-based clinical research networks, and for the continued success of the 27 Institutes and Centers of the National Institutes of Health (NIH). Increased funding can lead to significant change by halting the erosion of the nation’s medical research efforts, as well as help develop cutting-edge medicine, techniques, and treatments to ensure the good health of millions of Americans.

Research Funding Leads to Better Health Information

The AAO-HNS is grateful for the attention that Congress has paid to medical research in many areas, including tinnitus. NIDCD is to be commended for convening the “Brain Stimulation for Treatment of Tinnitus” workshop in August 2009. This meeting brought together the best minds from NIDCD, the Department of Defense, the Department of Veterans’ Affairs, and the Food and Drug Administration to discuss treatment in civilian, veteran, and active duty patients. We are confident that the NIDCD will continue to encourage novel treatment research in this area.

We are also interested in the recent results of a study published in the *Journal of the American Medical Association* on the effectiveness of early infant screening measures for identifying cytomegalovirus (CMV) infection, a leading cause of hearing loss in children. The study, which was funded by NIDCD, found that the traditional “heel-stick” procedure may not be a reliable screening tool for CMV. The AAO-HNS supports continued research of alternative early hearing screens and efforts to effectively ensure the timely diagnosis of CMV.

With regard to vocal health, the AAO-HNS celebrated World Voice Day on April 16, 2010, and this year's theme is "Love Your Voice." World Voice Day is intended to make people aware of the value and significance of vocal health in everyday life. We encourage men and women, young and old, to assess their vocal health and take action to improve or maintain good voice habits.

According to our statistics, more than one in four people in the United States report voice disorders during their lifetimes, and this number increases to more than one in two for high-risk professions such as teaching or being a Member of Congress.

Recently, just in time for March Madness, Lee M. Akst, MD, Director of the Johns Hopkins Voice Center, stated: "Yelling at basketball and baseball games, talking too much on your cell phone, and other forms of overuse can damage your voice. Red flags for an over-used voice are frequent hoarseness, a sense of strain while talking, or discomfort while speaking. If hoarseness lasts for more than two weeks or is accompanied by ear pain, difficulty breathing, or difficulty swallowing, it may indicate a potentially serious vocal cord condition. If these symptoms occur, then you should be evaluated by an ear-nose-throat specialist as quickly as possible."

In closing, we again want to thank you, Mr. Chairman and the members of the Subcommittee, for your attention. Your support for medical research is critical and valued.

Fiscal Year 2011 Appropriations

Submitted by: Sandy Harding, MSW, Director, Federal Affairs, sharding@aapa.org, 703-836-2772

TESTIMONY OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS
SUBMITTED TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
UNITED STATES House of Representatives
REGARDING FISCAL YEAR 2011 APPROPRIATIONS

April 13, 2010

On behalf of the nearly 80,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on FY 2011 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the Academy supports the HPNEC recommendation to provide at least \$330 million for Title VII programs in FY 2011, including a minimum of \$7 million to support PA educational programs. This would fund the programs at the 2005 funding level, not accounting for inflation.

AAPA recommends that Congress provide additional support to grow the PA primary care workforce through health care reform initiatives. A reformed health care system will require a much-expanded primary health care workforce, both in the private and public health care markets. For example, the National Association of Community Health Centers' March 2009 report, *Primary Care Access: An Essential Building Block of Health Reform*, predicts that in order to reach 30 million patients by 2015, health centers will need at least an additional 15,585 primary care providers, just over one third of whom are non-physician primary care professionals.

The Academy believes that the recommended restoration in funding for Title VII health professions programs is well justified.

A review of PA graduates from 1990 – 2009 demonstrates that PAs who have graduated from PA educational programs supported by Title VII are 67% more likely to be from underrepresented minority populations and 47% more likely to work in a rural health clinic than graduates of programs that were not supported by Title VII.

A study by the UCSF Center for California Health Workforce Studies found a strong association between physician assistants exposed to Title VII during their PA educational preparation and those who ever reported working in a federally qualified health center or other community health center.

Title VII safety net programs are essential to the development and training of primary health care professionals and, in turn, provide increased access to care by promoting health care delivery in medically underserved communities. Title VII funding is especially important for PA programs as it is the only federal funding available on a competitive application basis to these programs.

The AAPA is very appreciative of the recent funding increases, for the Title VII Health Professions Programs, in the FY 2009 Omnibus Appropriations bill (P.L. 111-8), which appropriated \$221.7 million, a 14.3% increase, over FY'08 and the American Recovery and Reinvestment Act (P.L.111-5), which invested \$200 million in expanding Title VII Health Professions Programs. However, the AAPA believes that these recent investments only begin to rectify the chronic underfunding of these programs and address existing and looming shortages of health professionals, especially physician assistants. According to HRSA, an additional 30,000 health practitioners are needed to alleviate existing health professional shortages.

We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support to restore funding to these important programs in FY 2010 to the FY 2005 funding level.

Overview of Physician Assistant Education

Physician assistant programs train students to practice medicine with physician supervision. PA programs are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 26 months of instruction, and the typical student has a bachelor's degree and about four years of prior health care experience. The first phase of the program consists of intensive classroom and laboratory study. More than 400 hours in classroom and laboratory instruction are devoted to the basic sciences, with over 75 hours in pharmacology, approximately 175 hours in behavioral sciences, and almost 580 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours, or 50-55 weeks, to clinical education, divided between primary care medicine – family medicine, internal medicine, pediatrics, and obstetrics and gynecology – and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

After graduation from an accredited PA program, physician assistants must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education hours every two years, and they must take a recertification exam every six years.

Physician Assistant Practice

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all states, physicians may delegate to PAs those medical duties that are allowed by law and are within the physician's scope of practice and the PA's training and experience. All states, the District of Columbia, and Guam authorize physicians to delegate prescriptive privileges to the PAs they supervise. Nineteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician). Approximately 41 percent of PAs work in urban and inner city areas. Approximately 40 percent of PAs are in primary care. Roughly 80 percent of PAs practice in outpatient settings AAPA estimates that in 2008, over 257 million patient visits were made to PAs and approximately 332 million medications were written by PAs.

Critical Role of Title VII Public Health Service Act Programs

Title VII programs promote access to health care in rural and urban underserved communities by supporting educational programs that train health professionals in fields experiencing shortages, improve the geographic distribution of health professionals, increase access to care in underserved communities, and increase minority representation in the health care workforce.

Title VII programs are the only federal educational programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the nation's medically underserved communities – the purpose of Title VII.

Furthermore, Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations, which is a critical step towards reducing persistent health disparities among certain racial and ethnic U.S. populations. Studies have found that health professionals from disadvantaged regions of the country are three to five times more likely to return to underserved areas to provide care.

It is also important to note that a December 2008 Institute of Medicine report characterized HRSA's health professions programs as "an undervalued asset."

Title VII Support of PA Educational Programs

Targeted federal support for PA educational programs is authorized through section 747 of the Public Health Service Act. The program was reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, P.L. 105-392, which streamlined and consolidated the federal health professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry.

P.L. 105-392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and operate accredited programs for the education of physician assistants, with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to

an affordable education and encourage PAs, upon graduation, to practice in underserved communities. **These goals are accomplished by funding PA educational programs that have a demonstrated track record of: 1) placing PA students in health professional shortage areas; 2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and 3) recruiting and retaining students who are indigenous to communities with unmet health care needs.**

The PA programs' success in recruiting and retaining underrepresented minority and disadvantaged students is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. One Texas program uses Title VII funds for the development of Web based and distant learning technology and methodologies so students can remain at clinical practice sites. In New York, a PA program with a 90% ethnic minority student population uses Title VII funding to focus on primary care training for underserved urban populations by linking with community health centers, which expands the pool of qualified minority role models that engage in clinical teaching, mentoring, and preceptorship for PA students. Several other PA programs have been able to use Title VII grants to leverage additional resources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training.

Without Title VII funding, many of these special PA training initiatives would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the needs of medically underserved areas or disadvantaged students. The need is very real, and Title VII is critical in meeting that need.

Need for Increased Title VII Support for PA Educational Programs

Increased Title VII support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 36 percent of PAs met their first clinical employer through their clinical rotations.

Changes in the health care marketplace reflect a growing reliance on PAs as part of the health care team. Currently, the supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 2006 article in the Journal of the American Medical Association (JAMA) concluded that the federal government should augment the use of physician assistants as physician substitutes, particularly in urban CHCs where the proportional use of physicians is higher. The article suggested that this could be accomplished by adequately funding Title VII programs. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 39 percent between 2008 and 2018. Title VII funding has provided a crucial pipeline of trained PAs to underserved areas. One way to assure

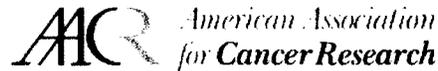
an adequate supply of physician assistants practicing in underserved areas is to continue offering financial incentives to PA programs that emphasize recruitment and placement of PAs interested in primary care in medically underserved communities.

Despite the increased demand for PAs, funding has not proportionately increased for Title VII programs that educate and place physician assistants in underserved communities. Nor has Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budgets from 1984 through 2004 indicates an average annual increase of seven percent, a total increase of 256 percent over the past 20 years, as federal support has decreased.

Recommendations on FY 2011 Funding

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and programs when determining funding for FY 2010. For instance, while it is critical, now more than ever, to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration is inadequately funded. HRSA administers the "people" programs, such as Title VII, that bring the results of cutting edge research at NIH to patients through providers such as PAs who have been educated in Title VII-funded programs. Likewise, CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

The Academy respectfully requests that Title VII health professions programs receive \$330 million in funding for FY 2011, including a minimum of \$7 million to support PA educational programs. Thank you for the opportunity to present the American Academy of Physician Assistants' views on FY 2011 appropriations.



Written Testimony
from the
American Association for Cancer Research (AACR)
April 16, 2010

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The American Association for Cancer Research (AACR) recognizes and expresses its thanks to the United States Congress for its longstanding support and commitment to funding cancer research. The continuing investment in research through the American Recovery and Reinvestment Act of 2009 (ARRA) and the fiscal year 2010 budget will support current projects and provide for new efforts in the fight against cancer. These new efforts are now underway and promise to yield innovative and potentially breakthrough approaches to understanding, preventing, treating and ultimately curing cancer. The full potential, however, will not be fully realized in a short one- or two-year period. Sustained, stable funding through regular appropriations will be necessary to allow researchers to uncover the discoveries today that will lead to more lives saved tomorrow.

Unquestionably, the nation's investment in cancer research is having a remarkable impact. Cancer deaths in the United States have declined in recent years. This progress is occurring in spite of an aging population and the fact that more than three-quarters of all cancers are diagnosed in individuals aged 55 and older. Yet this good news will not continue without stable and sustained federal funding for critical cancer research priorities.

The American Association for Cancer Research urges the United States House of Representatives to strongly support biomedical research funding at the National Institutes of Health (NIH), including carrying out President Obama's vision for doubling cancer research funding in order to find a cure for cancer in our time. Therefore, the AACR supports the biomedical community's recommendation of sustaining the current funding for NIH, which would amount to \$35.2 billion in FY2011.

AACR: Fostering a Century of Research Progress

The American Association for Cancer Research has been moving cancer research forward since its founding in 1907. Celebrating its 101st Annual Meeting in Washington, D.C., this April, the AACR and its more than 30,000 members worldwide strive tirelessly to carry out its important

mission to prevent and cure cancer through research, education, and communication. It does so by:

- fostering research in cancer and related biomedical science;
- accelerating the dissemination of new research findings among scientists and others dedicated to the conquest of cancer
- promoting science education and training; and
- advancing the understanding of cancer etiology, prevention, diagnosis, and treatment throughout the world.

Facing an Impending Cancer "Tsunami"

Over the last century, enormous progress has been made toward the conquest of the nation's second most lethal disease (after heart disease). Thanks to discoveries and developments in prevention, early detection, and more effective treatments, many of the more than 200 diseases called cancer have been cured or converted into manageable chronic conditions while preserving quality of life. The five-year survival rate for all cancers has improved over the past 30 years to more than 65 percent. The completion of the doubling of the NIH budget in 2003 is bearing fruit as many new and promising discoveries are unearthed and their potential realized. However, there is much left to be done, especially for the most lethal and rare forms of the disease.

We recognize that the underlying causes of the disease and its incidence have not been significantly altered. The fact remains that men have a one in two lifetime risk of developing cancer, while women have a one in three lifetime risk. The leading cancer sites in men are the prostate, lung and bronchus, and colon and rectum. For women, the leading cancer sites are breast, lung and bronchus, and colon and rectum. And cancer still accounts for one in four deaths, with more than half a million people expected to die from their cancer in 2010. Age is a major risk factor — this nation faces a virtual "cancer tsunami" as the baby boomer generation reaches age 65 in 2011. A renewed commitment to progress in cancer research through leadership and resources is essential to avoid this cancer crisis.

Blueprint for Progress: NCI's Strategic Objectives

Basic, translational, and clinical cancer research in this country are conducted primarily through three venues — government, academia and the nonprofit sector, and the pharmaceutical/biotechnology industry. The Congress provides the appropriations for the National Institutes of Health and the National Cancer Institute (NCI), through which most of the government's research on cancer is conducted. The NCI has developed documents and processes that describe and guide its priorities — established with extensive community input — for the use of these finite resources. "The NCI Strategic Plan for Leading the Nation" and "The Nation's Investment in Cancer Research: An Annual Plan and Budget Proposal Fiscal Year 2011" are the recognized professional blueprints for what needs to be done to accelerate progress against cancer.

The American Association for Cancer Research and many in the cancer research community concur that if the NCI receives the increased investment of \$1.2 billion as proposed for FY2011, the NCI will have the capability to rebuild America's research infrastructure capacity and accelerate research progress in critical priority areas:

- understanding the causes and mechanisms of cancer;
- accelerating progress in cancer prevention;

- improving early detection and diagnosis;
- developing effective and efficient treatments;
- understanding the factors that influence cancer outcomes;
- improving the quality of cancer care;
- improving the quality of life for cancer patients, survivors, and their families; and
- overcoming cancer health disparities.

Federal Investment for Local Benefit

Over half of the NCI budget is allocated to research project grants that are awarded to outside scientists who work at local hospitals and universities throughout the country. More than 6,500 research grants are funded at more than 150 cancer centers and specialized research facilities located in 49 states. In over half the states, grants and contracts to institutions exceed \$15 million. This federal investment also provides needed economic stimulus to local economies. For example, on average, each dollar of NIH funding generated more than twice as much in state economic output in fiscal year 2007. Many AACR member scientists across the nation are engaged in this rewarding work, and many have had their long-term research jeopardized by grant reductions caused by the flat and declining overall funding for the NCI since 2003. The recent increase in fiscal year 2010 appropriations and the ARRA funding will help to revitalize America's research infrastructure; however, sustained and stable funding is critical to reap the benefits of this investment. Thus, the AACR supports sustaining the current investment in the NCI with a budget of \$5.8 billion.

Understanding the Causes and Mechanisms of Cancer

Basic research into the causes and mechanisms of cancer is at the heart of what the NCI and many of AACR's member scientists do. The focus of this research includes: investigating the underlying basis of the full spectrum of genetic susceptibility to cancer; identifying the influence of the macroenvironment (tumor level) and microenvironment (tissue level) on cancer initiation and progression; understanding the behavioral, environmental, genetic, and epigenetic causes of cancer and their interactions; developing and applying emerging technologies to expand our knowledge of risk factors and biologic mechanisms of cancer; and elucidating the relationship between cancer and other human diseases.

Basic research is the engine that drives scientific progress. The outcomes from this fundamental basic research — including laboratory and animal research, in addition to population studies and the deployment of state-of-the-art technologies — will inform and drive the cancer research enterprise in ways and directions that will lead to unparalleled progress in the search for cures.

Accelerating Progress in Cancer Prevention

Preventing cancer is far more cost-effective and desirable than treating it. NCI's strategic plan supports research in: understanding and modifying behaviors that increase risk; reducing the influence of genetic and environmental risk factors; and interrupting the initiation of cancer through early medical intervention. A critical component of this multifaceted approach is ensuring that evidence-based advances that have been shown to inform and motivate people toward healthy behaviors are widely disseminated and accessible.

The NCI uses multidisciplinary teams and a systems biology approach to identify early events and determine how to modify them. More than half of all cancers are related to modifiable behavioral factors, including tobacco use, diet, physical inactivity, sun exposure, and failure to get cancer screenings. The NCI supports research to understand how people perceive risk, make health-related decisions, and maintain healthy behavior. Prevention is the keystone to success in the battle against cancer.

Developing Effective and Efficient Treatments

The future of cancer care is all about developing individualized therapies tailored to the specific characteristics of a patient's cancer. The NCI's research in this area concentrates on: identifying the determinants of metastatic behavior; validating cancer biomarkers for prognosis, metastasis, treatment response, and progression; accelerating the identification and validation of potential cancer molecular targets; minimizing the toxicities of cancer therapy; and integrating the clinical trial infrastructure for speed and efficiency. The completion of the Human Genome Project and breakthroughs resulting from The Cancer Genome Atlas project are leading the way toward an era of personalized medicine.

Overcoming Cancer Health Disparities

Some minority and underserved population groups suffer disproportionately from cancer. Solving this issue will contribute significantly to reducing the cancer burden. The NCI's investments in this area include: studying the factors that cause cancer health disparities; working with underserved communities to develop targeted interventions; developing the knowledge base for integrating cancer services to the underserved; collaborating to implement culturally appropriate information dissemination approaches to underserved populations; and examining the role of health policy in eliminating cancer health disparities. One size does not fit all in cancer research — special populations require special treatment to achieve success.

Training and Career Development for the Next Generation of Researchers

Of critical importance to the viability of the long-term cancer research enterprise is supporting, fostering, and mentoring the next generation of investigators. The NCI historically devotes approximately four percent of its budget to support training and career development, including sponsored traineeships, a Medical Scientist Training Program, special set-aside grant programs, and bridge grants for early career cancer investigators. Increased funding for these foundational opportunities is essential to retain the scientific workforce that is needed to continue the fight against cancer.

AACR's Initiatives Augment Support for the NCI

The NCI is not working alone or in isolation in any of these key areas. NCI research scientists reach out to other organizations to further their work. The AACR is engaged in scores of initiatives that strengthen, support, and facilitate the work of the NCI. Just a few of AACR's contributions include:

- sponsoring the largest meeting of cancer researchers in the world, with more than 14,000 scientists, where 6,000 scientific abstracts featuring the latest basic, translational, and clinical scientific advances are presented;

- publishing more than 3,400 original research articles each year in six prestigious peer-reviewed scientific journals, including *Cancer Research*, the most frequently cited cancer journal;
- sponsoring the annual International Conference on Frontiers of Cancer Prevention Research, the largest such prevention meeting of its kind in the world;
- supporting the work of the AACR Chemistry in Cancer Research Working Group;
- convening and supporting the AACR-FDA-NCI Cancer Biomarkers Collaborative;
- hosting, with NCI, the Molecular Targets and Cancer Therapeutics Conference;
- sponsoring and supporting a Minorities in Cancer Research Council and a Women in Cancer Research Council;
- conducting the scientific review and grants administration for the over \$100 million donated to Stand Up To Cancer; and
- raising and distributing more than \$5 million in awards and research grants.

Stable, Sustained Increases in Research Funding

Remarkable progress is being made in cancer research, but much more remains to be done. Cancer costs the nation more than \$228 billion in direct medical costs and lost productivity due to illness and premature death. Respected University of Chicago economists Kevin Murphy and Robert Topel have estimated that even a modest one percent reduction in mortality from cancer would be worth nearly \$500 billion in social value. In addition, investments in cancer research stimulate the local economy today and promise huge potential returns in the future. Thanks to successful past investments, promising research opportunities abound and must not be lost. To maintain our research momentum, the American Association for Cancer Research urges the United States House of Representatives to support a budget of \$35.2 billion for the National Institutes of Health, including \$5.8 billion for the National Cancer Institute.

Written Statement
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to the
House Subcommittee on Labor, Health and Human Services,
Education, & Related Agencies
on behalf of the
National Institute of Dental and Craniofacial Research
April 12, 2010

Introduction

Mr. Chairman and members of the Committee, I am David Wong, Director of the Dental Research Institute at the University of California, Los Angeles (UCLA) School of Dentistry. My testimony is on behalf of the American Association for Dental Research (AADR).

I thank the committee for this opportunity to testify about the exciting advances in oral health science. Research funded by the National Institutes of Health (NIH) has returned significant dividends in terms of recent advances in health care, including dental care and oral health research thanks to the efforts of the National Institute of Dental and Craniofacial Research (NIDCR). Since 1948, NIDCR has conducted research, trained researchers, and disseminated health information in order to improve the health of Americans and make it possible for them to live longer and healthier lives.

What Is the American Association for Dental Research?

The American Association for Dental Research (AADR), headquartered in Alexandria, Va., is a nonprofit organization with more than 4,000 individual members and 100 institutional members within the United States. Its mission is: 1) to advance research and increase knowledge for the improvement of oral health; 2) to support and represent the oral health research community; and 3) to facilitate the communication and application of research findings. AADR is the largest Division of the International Association for Dental Research (IADR).

Why Oral Health Is Important

Oral health is an essential component of health throughout life. Poor oral health and untreated oral diseases and conditions can have a significant impact on quality of life. They can affect the most significant human needs including the ability to eat and drink, swallow, maintain proper nutrition, smile, and communicate.

Over the past fifty years, there has been a dramatic improvement in oral health. Still, oral diseases remain a major concern. Oral health and general health are inseparable. Diseases and conditions of the mouth have a direct impact on the health of the entire body.

Good oral health can help improve birth outcomes, keep children from developing painful cavities and prevent seniors, and those with chronic health conditions, from developing life-threatening complications. In recent years, new scientific reports have linked poor oral health to poor general health. Dental decay (cavities) is one of the most common chronic illnesses among children. Although most dental diseases are preventable, many children unnecessarily suffer from dental disease because of inadequate home care and lack of access to dental services. An estimated 51 million school hours per year are lost in the U.S. because of dental-related illness. Poor oral health has been related to decreased school performance, poor social relationships and less success later in life.

Employed adults in the United States lose more than 164 million hours of work each year as a result of oral health problems or dental visits. About 30 percent of adults 65 years old and older have lost all of their natural teeth. Older Americans with the poorest oral health are those who are economically disadvantaged, lack insurance and are members of racial and ethnic minorities. As the nation ages, oral health issues related to gum disease and the impact of medical treatments and medicines will increase. Maintaining good oral health throughout a person's life is important.

Research Accomplishments

Oral and Systemic Health - The oral cavity plays an important role in the overall health of the body. Some say the mouth is the body's mirror. And while associations between oral and systemic health can be made, specific cause-and-effect relationships remain elusive. It has been reported that 3 out of every 4 Americans have signs of mild periodontal disease. Almost 30% show signs of the more severe disease, chronic periodontitis. We now have reason to believe that the health of your teeth and gums may have a significant effect on the overall health of your body. Recent scientific literature suggests a strong relationship between oral disease and other systemic diseases and medical conditions.

According to numerous studies, there are three ways oral disease may affect your overall health. First, bacteria from your gums enter the saliva. From the saliva it may adhere to water droplets within the air you inhale each time you breathe. These bacteria laden water droplets may be aspirated into the lungs, potentially causing pulmonary infection and pneumonia. This can be a serious problem for the elderly or those who may suffer from generalized weakened immunity, associated with chronic obstructive pulmonary disease (COPD). Inflammatory mediators found in inflamed gums called "cytokines" can also enter your saliva.

Secondly, bacteria associated with periodontal disease can enter the body's circulatory system through the gums (periodontium) around teeth and travel to all parts of the body. As the oral bacteria travels, it may cause secondary infections or it may contribute to the disease process in other tissues and organ systems.

Finally, inflammation associated with periodontal disease may stimulate a second systemic inflammatory response within the body and contribute to or complicate other disease entities that may have an inflammatory origin such as, cardiovascular disease, diabetes, and kidney disease.

The goal of many studies being conducted at dental schools and research centers throughout the world is to understand just how oral bacteria affect overall health. As these studies are published, health care professionals will begin to better understand the underlying biological mechanisms that are responsible for this oral systemic connection.

Health Disparities – Despite remarkable improvements in the oral health of many, not everyone in the nation has benefited equally. Oral, dental and craniofacial conditions remain among the most common health problems for low-income, racial/ethnic minority, disadvantaged, disabled, and institutionalized individuals across the life span. Dental caries, periodontal diseases, and oral and pharyngeal cancer are of particular concern.

The NIDCR Health Disparities Research Program supports studies that:

- Provide a better understanding of the basis of health disparities and inequalities;
- Develop and test interventions tailored and targeted to underserved populations; and
- Explore approaches to the dissemination and implementation of effective findings to assure rapid translation into practice, policy and action in communities.

The NIDCR supports:

- Research that seeks to understand a broadened array of determinants of disparities/inequalities in oral health status and care at multiple levels;
- Interventional research designed to have a meaningful impact on oral health status and quality of life that will influence action in health care, public policy, or diseases/disability prevention in communities;
- Cost analyses of interventions as well as comparative effectiveness studies;
- Behavioral and social science intervention research that is grounded in theory and considers mechanisms of action;
- Research that utilizes new technologies and approaches that are practical, culturally appropriate and sustainable for individuals, caregivers and workers.
- Novel interventions as well as those that have previously been untested with vulnerable populations.

Researchers from many backgrounds and disciplines contribute to health disparities/inequalities research. Some of the disciplines of researchers on health disparities/inequalities research teams are genetics, dentistry and dental hygiene, and medicine and nursing. Teams that conceptualize, plan and conduct this type of research include community members of the disadvantaged and vulnerable population subgroups as partners in the research enterprise.

Salivary Diagnostics - Oral and systemic diseases can be difficult to diagnose, involving complex clinical evaluation and/or blood and urine tests that are labor intensive, expensive, and invasive. Now, after years of research, saliva is poised to be used as a non-invasive diagnostic

fluid for a number of oral and systemic conditions. Salivary diagnostics has come of age. In just a little over six years, research supported by the National Institute of Dental Craniofacial Research (NIDCR) has sprung to the forefront of basic, translational, and clinical research. Saliva not only combats bacteria and viruses that enter the mouth, but it also serves as a first line of defense in oral and systemic diseases. It contains many compounds indicating a person's overall health and disease status and, like blood or urine, its composition may be altered in the presence of a disease. Saliva is very easy to collect, providing a major advantage over the use of blood or urine for diagnostic tests. Saliva has the same biomarkers found in blood and urine.

Oral cancer affects 38,000 Americans each year. The death rate associated with this cancer is especially high due to delayed diagnosis. Saliva is not only more accurate than blood for oral cancer detection, but saliva diagnostics will likely outperform other biomedica for other disease diagnostics as well. The risk of oral cancer, prostate cancer, breast cancer, and a host of other health conditions can be determined and often prevented when acting on information provided from a saliva hormonal assay. Saliva tests could prove to be a potentially life-saving alternative to detect diseases where early diagnosis is critical, such as certain cancers. For most cancers, successful treatment depends on early detection and successful prevention depends on the accurate evaluation of risk. Early detection of oral cancer will increase survival rate, improve the quality of life of cancer patients, and will result in a significant reduction in health care costs.

Conclusion

As you can see, Mr. Chairman, there are many research opportunities with an immediate impact on patient care that need to be pursued. A consistent and reliable funding stream for NIH overall, and NIDCR in particular, is essential for continued improvement in the oral health of Americans.

In order to sustain momentum in the field of oral and systemic health, health disparities, and salivary diagnostics, it is requested that NIH receive a fiscal year 2011 appropriation of \$35 billion, of which NIDCR should receive an FY 2011 appropriation of \$481 million.

Thank you for the opportunity to testify.

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**Statement of the American Association for Geriatric Psychiatry
To the Subcommittee on Labor, Health and Human Services, and Education
U. S. House of Representatives Committee on Appropriations
On FY 2011 Appropriations for the Department of Health and Human Services
April 16, 2010**

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to comment on issues related to fiscal year (FY) 2011 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by aging adults.

AAGP appreciates the work this Subcommittee has done in recent years in support of funding for research and services in the area of mental health and aging through the National Institutes of Health and the Substance Abuse and Mental Health Services Administration. Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

A National Health Crisis: Demographic Projections and the Mental Disorders of Aging

The aging of the baby boomer generation will result in an increase in the proportion of persons over 65 from 12.7 percent currently to 20 percent in 2030, with the fastest growing segment of the population consisting of age 85 and older. During the same period, the number of older adults with major psychiatric illnesses will more than double, from an estimated 7 million to 15 million individuals, meeting or exceeding the number of consumers in discrete, younger age groups.

The cost of treating mental disorders can be staggering. For example, it is estimated that total costs associated with the care of patients with Alzheimer's disease is over \$100 billion per year in the United States. Psychiatric symptoms (including depression, agitation, and psychotic symptoms) affect 30 to 40 percent of people with Alzheimer's and are associated with increased hospitalization, nursing home placement, and crippling family burden. These psychiatric symptoms can increase the cost of treating these patients by more than 20 percent. However, these costs pale when compared to the costs of not treating mental disorders including lost work time, co-morbid illness, and increased nursing home utilization. It is also important to note the added burden, financial and emotional, on family caregivers, as the nation's informal caregiving system is already under tremendous strain and will require more support in the years to come.

Depression is another example of a common diagnosis among older persons. Of the approximately 32 million Americans who have attained age 65, about five million suffer from depression, resulting in increased disability, general health care utilization, and risk of suicide. Depression is associated with poorer health outcomes and higher health care costs. Those with depression are more likely to be hospitalized and experience almost twice the number of medical visits than those without depression. Finally, the cost and number of prescriptions for this group were more than twice than those without depression.

Older adults also have the highest rate of suicide compared to any other age group. The suicide rate for those 85 and older is twice the national average. More than half of older persons who commit suicide visited their primary care physician in the prior month.

Preparing a Workforce to meet the Mental Health Needs of the Aging Population

In 2008, the Institute of Medicine (IOM) released a study of the readiness of the nation's healthcare workforce to meet the needs of its aging population. *The Re-tooling for an Aging America: Building the Health Care Workforce* called for immediate investments in preparing our health care system to care for older Americans and their families. AAGP is deeply grateful to this subcommittee for providing, in the appropriations bill for FY 2010, funding for a follow-up study of the current and projected mental and behavioral healthcare needs of the American people, particularly for aging and growing ethnic populations. This study will complement the 2008 IOM study by providing in-depth consideration of the mental health needs of geriatric and ethnic minority populations that were precluded by the broad scope of the earlier one.

Virtually all health care providers need to be fully prepared to manage the common medical and mental health problems of old age. In addition, the number of geriatric health specialists, including mental health providers, needs to be increased both to provide care for those older adults with the most complex issues and to train the rest of the workforce in the common medical and mental health problems of old age. The small numbers of specialists in geriatric mental health, combined with increases in life expectancy and the growing population of the nation's elderly, foretells a crisis in health care that will impact older adults and their families nationwide. Unless changes are made now, older Americans will face long waits, decreased choice, and suboptimal care.

Already, there are programs administered by the Bureau of Health Professions in the HHS Health Resources and Services Administration (HRSA) administers that are aimed to help to assure adequate numbers of health care practitioners for the nation's geriatric population, especially in underserved areas. The breadth of these programs has been strengthened by provisions included in the recently enacted Patient Protection and Affordable Care Act (PPACA).

The geriatric health professions program supports these important initiatives:

- The Geriatric Education Center (GEC) program provides interdisciplinary training for health care professionals in assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans. PPACA authorizes \$10.8

million in supplemental grants for the GEC Program to support training in geriatrics, chronic care management, and long-term care for faculty in a broad array of health professions schools, as well as direct care workers and family caregivers. GECs receiving these grants are required to develop and include material on depression and other mental disorders common among older adults, medication safety issues for older adults, and management of the psychological and behavioral aspects of dementia in all appropriate training courses.

- The Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Professionals (GTPD Program) provides fellows with exposure to older adult patients in various levels of wellness and functioning and from a range of socioeconomic and racial/ethnic backgrounds.
- The Geriatric Academic Career Awards (GACA) support the academic career development of geriatric specialists in junior faculty positions who are committed to teaching geriatrics in professional schools. PPACA expands the disciplines eligible for the awards. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of health care professionals.
- PPACA authorized a new Geriatric Career Incentive Awards Program in Title VIII of the Public Health Service Act for grants to foster great interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. This program was authorized for \$10 million over three years.
- A new program, authorized by PPACA at \$10 million for three years, will provide advanced training opportunities for direct care workers in the field of geriatrics, long term-care or chronic care management.

AAGP strongly supports increased funding for the existing programs, particularly as the disciplines included have been expanded, and funding to fully authorized levels for the new programs.

National Institutes of Health (NIH) and National Institute of Mental Health (NIMH)

With the graying of the population, mental disorders of aging represent a growing crisis that will require a greater investment in research to understand age-related brain disorders and to develop new approaches to prevention and treatment. Even in the years in which funding was increased for NIH and the NIMH, these increases did not always translate into comparable increases in funding that specifically address problems of older adults. For instance, according to figures provided by NIMH, NIMH total aging research amounts decreased from \$106,090,000 in 2002 to \$85,164,000 in 2006 (dollars in thousands: \$106,090 in 2002, \$100,055 in 2003, \$97,418 in 2004, \$91,686 in 2005, \$85,164 in 2006).

The critical disparity between federally funded research on mental health and aging and the projected mental health needs of older adults is continuing. If the mental health research budget for older adults is not substantially increased immediately, progress to reduce mental illness among the growing elderly population will be severely compromised. While many different

types of mental and behavioral disorders occur in late life, they are not an inevitable part of the aging process, and continued and expanded research holds the promise of improving the mental health and quality of life for older Americans. This trend must be immediately reversed to ensure that our next generation of elders is able to access effective treatment for mental illness. Federal funding of research must be broad-based and should include basic, translational, clinical, and health services research on mental disorders in late life.

AAGP believes that it is critical that NIH begin to invest increased funding in future evidence-based treatments for our nation's elders. Annual increases of funds targeted for geriatric mental health research at NIH should be used to: (1) identify the causes of age-related brain and mental disorders to prevent mental disorders before they devastate lives; (2) speed the search for effective treatments and efficient methods of treatment delivery; and (3) improve the quality of life for older adults with mental disorders.

Participation of Older Adults in Clinical Trials

Federal approval for most new drugs is based on research demonstrating safety and efficacy in young and middle-aged adults. These studies typically exclude people who are old, who have more than one health problem, or who take multiple medications. As the population ages, that is the very profile of many people who seek treatment. Thus, there is little available scientific information on the safety of drugs approved by the Food and Drug Administration (FDA) in substantial numbers of older adults who are likely to take those drugs. Pivotal regulatory trials never address the special efficacy and safety concerns that arise specifically in the care of the nation's mentally ill elderly. This is a critical public health obligation of the nation's health agencies. Just as the FDA has begun to require inclusion of children in appropriate studies, the agency should work closely with the geriatric research community, health care consumers, pharmaceutical manufacturers, and other stakeholders to develop innovative, fair mechanisms to encourage the inclusion of older adults in clinical trials. Clinical research must also include elders from diverse ethnic and cultural groups. In addition, AAGP urges that Federal funds be made available each year for support of clinical trials involving older adults.

Study on NIH Funding for Mental Disorders among Older Adults

As little emphasis has been placed on the development of new treatments for geriatric mental disorders, AAGP encourages NIH to promote the development of new medications specifically targeted at brain-based mental disorders of the elderly. AAGP urges this Committee to request a GAO study on spending by NIH on conditions and illnesses related to the mental health of older individuals. NIH has already undertaken, in its Blueprint for Neuroscience Research, an endeavor to enhance cooperative activities among NIH Institutes and Centers that support research on the nervous system. A GAO study of the work being done by these 16 institutes in areas that predominately involve older adults could provide crucial insights into possible new areas of cooperative research, which in turn will lead to advances in prevention and treatment for these devastating illnesses.

Center for Mental Health Services

It is critical that there be adequate funding for the mental health initiatives under the jurisdiction of the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental

Health Services Administration (SAMHSA). While research is of critical importance to a better future, today's patients must also receive appropriate treatment for their mental health problems.

Evidence-based Mental Health Outreach and Treatment for the Elderly

While research is of critical importance to a better future, the patients of today must also receive appropriate treatment for their mental health problems. AAGP was pleased that the final SAMHSA budgets for the last nine years have included \$5 million for evidence-based mental health outreach and treatment to the elderly. AAGP worked with members of this Subcommittee and its Senate counterpart on this initiative, and urges an increase in funding from \$5 million to \$10 million for this essential program to disseminate and implement evidence-based practices in routine clinical settings across the states.

Centers of Excellence for Depressive and Bipolar Disorders

PPACA also included authorization for a new national network of centers of excellence for depressive and bipolar disorders, which will enhance the coordination and integration of physical, mental and social care that are critical to the identification and treatment of depression and other mental disorders across the lifespan. The work of these centers will help to disseminate and implement evidence-based practices in clinical settings throughout the country. AAGP strongly supports funding for the centers authorized by this legislation.

Conclusion

AAGP recommends:

- Increased funding for the geriatric health professions education programs under Title VII of the Public Health Service Act and full funding for new programs authorized by the PPACA;
- Funding to support clinical trials involving older adults;
- A GAO study on spending by NIH on conditions and illnesses related to the mental health of older individuals;
- Increased funding for evidence-based geriatric mental health outreach and treatment programs at CMHS;
- Funding for Centers of Excellence for Depressive and Bipolar Disorders.



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Testimony of the American Association of Colleges of Nursing Regarding

Fiscal Year 2011 Appropriations for the Title VIII Nursing Workforce Development Programs, the National Institute of Nursing Research, and the Capacity for Nursing Students and Faculty Program

U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and Education

Department of Health and Human Services

April 16, 2010

The American Association of Colleges of Nursing (AACN) respectfully submits this testimony highlighting funding priorities for nursing education and research programs in FY 2011. AACN represents nearly 650 schools of nursing at public and private institutions with baccalaureate and graduate nursing programs that include over 270,000 students and 13,000 faculty members. These institutions educate almost half of our nation's Registered Nurses (RNs) and all of the Advanced Practice Registered Nurses (APRNs), nurse faculty, and researchers.

The Nationwide Nursing Shortage

The United States is in the midst of a nursing shortage that has impacted the quality care in our nation's healthcare system for twelve years. The current economic downturn has led to a false impression that the nursing shortage is 'easing' in some parts of the country because hospitals are enacting hiring freezes and nurses are choosing to delay retirement. However, this trend is only temporary. More positions continue to open for RNs across the country due to factors such as an aging population, increased complexity of care, and a significant population with chronic diseases. Moreover, the new healthcare reform law will increase access to care, which will require a surge in the number healthcare providers. RNs and APRNs will be in high demand. This comes at a time when the U.S. Bureau of Labor Statistics (BLS), currently reports that nursing is the nation's top profession in terms of projected job growth with more than 581,000 new positions being created through 2018 (a 22% increase in the workforce). Unless we act *now*, this shortage will further jeopardize patient access to quality care.

Nursing and economic research clearly indicate that today's shortage is far worse than those of the past. The current supply and demand for nurses demonstrates two distinct challenges. First, due to the present and looming demand for health care by American consumers, the supply is not growing at a pace that will adequately meet long-term needs, including the demand for primary care, which is often provided by APRNs. This is further compounded by the number of nurses who will retire or leave the profession in the near future, ultimately reducing the nursing workforce. Second, the

supply of nurses nationwide is stressed due to capacity barriers in schools of nursing. According to AACN, 54,991 qualified applicants were turned away from baccalaureate and graduate nursing programs in 2009 primarily due to insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. Federal support for nursing education is critical at this juncture in American history. National reform goals cannot be met without an adequate number of nurses to provide the cost-effective and quality care associated with the nursing discipline.

Nursing Workforce Development Programs: A Proven Solution

For nearly five decades, the Title VIII Nursing Workforce Development Programs (42 U.S.C. 296 et seq.) have supported hundreds of thousands of nurses and nursing students. The Title VIII programs award grants to nursing education programs, as well as provide direct support to nurses and nursing students through loans, scholarships, traineeships, and programmatic grants.

The Nursing Workforce Development Programs are effective and meet their authorized mission. AACN's *2009-2010 Title VIII Student Recipient Survey* included responses from 1,420 students who noted that these programs played a critical role in funding their nursing education, which will ultimately help them to achieve future career goals. The students responding to the Title VIII survey have career aspirations that meet the direct needs of the healthcare system and the profession. A high percentage of the students surveyed (48.9%) reported that their career goal is to become a nurse practitioner. Given the demand for primary care providers, the Title VIII funds are helping to support the next generation of these essential practitioners. Moreover, the nurse faculty shortage continues to inhibit the ability of nursing schools to increase student capacity and address the shortage. Of the students who responded to the survey, 40.6% stated their ultimate career goal was to become nurse faculty. Providing support for Title VIII is the key to help schools expand student capacity, fill vacant nursing positions, and, in turn, improve healthcare quality.

While millions of Americans are struggling during this economic downturn and thousands of students need to obtain student loans for their education, federal support is greatly appreciated. The student recipients reported that more funding was needed for these programs to help offset the considerable cost of nursing education. Fifty-two percent of the students responded that the Title VIII funding paid for 25% or less of their total student loans. Of those students, 26% stated that the funding paid for less than 5% of their total nursing student loans.

Over the last 45 years, Congress has used the Title VIII authorities as a mechanism to address past nursing shortages. When the need for nurses was great, higher funding levels were appropriated. For example, during the nursing shortage in the 1970s, Congress provided \$160.61 million to the Title VIII programs in 1973. Adjusting for inflation to address the 37-year difference, \$160.61 million (FY 1973 funding level) in 2010 dollars would be approximately \$784 million. At a time when nursing economists project the current shortage to be twice as large as any nursing shortage experienced in this country since the mid-1960s, more must be invested in Title VIII to decrease the magnitude of the RN demand.

AACN respectfully requests \$267.3 million (a 10% increase) for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service in fiscal year (FY) 2011. Last year, your Subcommittee provided a significant funding boost for Title VIII that helped support the Loan Repayment and Scholarship program and Nurse Faculty Loan program. These increases will help bolster the pipeline of nurses and nurse faculty, which are so critical to reversing the nursing shortage. It is extremely important to maintain last year's funding

level for these crucial programs in FY 2011. AACN believes the 10% requested increase should be directed to the four Title VIII programs that have not kept pace with inflation since FY 2005. These programs include the Advanced Education Nursing, Nursing Workforce Diversity, Nurse Education, Practice, and Retention, and Comprehensive Geriatric Education programs, which help expand nursing school capacity and increase patient access to care. The 10% increase awarded to these programs in proportion to their FY 2010 funding level would be a wise investment of federal resources.

Nursing Research: Supporting Health Promotion & Disease Prevention

The National Institute of Nursing Research (NINR) is one of the 27 Institutes and Centers at the National Institutes of Health (NIH). As the nucleus for nursing science, NINR funds research that establishes the scientific basis for health promotion, disease prevention, and high quality nursing care services to individuals, families, and populations. Often working collaboratively with physicians and other researchers, nurse scientists are vital in setting the national research agenda. While medical research focuses on curing diseases, nursing research is conducted to *prevent* disease. The four strategic areas of emphasis for research at NINR are:

- **Promoting Health and Preventing Disease**
Presently, more than 1.7 million Americans die each year from chronic diseases. Nurse researchers focus on investigating wellness strategies to prevent these chronic diseases. A healthcare system that promotes prevention is a major focus of the new health reform law, and NINR is a leader in funding scientific research to discover optimal prevention methods.
- **Eliminating Health Disparities**
Race, gender, socioeconomic status, ethnic origin, geography, and culture impact the health care of individuals and communities. NINR is committed to funding research that investigates culturally appropriate interventions and care strategies focused on at-risk populations.
- **Improving Quality of Life**
Disease prevention is a critical goal of clinical research. NINR is committed to funding research that assists individuals with managing their own health conditions, decreases adverse symptoms, and reduces the burden on caregivers.
- **Setting Directions for End-of-Life Research**
Palliative care and respect for those at the end of their life is a critical part of treatment for serious and life-threatening illness. This care is provided alongside disease treatment to ease suffering and improve the quality-of-life for the patient. NINR seeks, through scientific research, to improve the understanding of the processes underlying palliative care efforts and develop effective strategies to optimize care across all patient populations.

Research conducted at NINR improves quality of care to benefit health both globally and nationally. With increased appropriations for NINR, more comprehensive, complex, and longitudinal studies could be funded in the areas provided below as well as meet the current goals, projects, and priorities of the Institute.

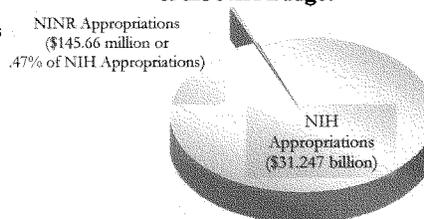
- **Expand the scope of science in symptom management**
- **Global health**
- **Increase funding for scientist-initiated research applications**

- **Expand the translation, dissemination, and outreach of NINR generated research to bridge the gap between scientific evidence and clinical practice.**
- **Evaluate the impact of nursing science on the health of the nation**
- **Support future nurse researchers**

Considering that NINR presently allocates 7% of its budget to training that helps develop the pool of nurse researchers, additional funding would support NINR's efforts to prepare faculty researchers needed to educate new nurses.

NINR's FY 2010 funding level of \$145.66 million is approximately 0.47% of the overall \$31.247 billion NIH budget (see Figure 1). Spending for nursing research is a modest amount relative to the allocations for other health science institutes and for major disease category funding. For NINR to adequately continue and further its mission, the institute must receive additional funding. Cuts in funding have impeded the institute from supporting larger comprehensive studies needed to advance nursing science and improve the quality of patient care.

Figure 1: FY 2010 NINR Appropriations as a Portion of the NIH Budget



Therefore, AACN respectfully requests \$160 million for the National Institute of Nursing Research, an additional \$14.34 million over the FY 2010 level.

The Capacity for Nursing Students and Faculty Program, Section 804 of the Higher Education Opportunity Act of 2008 (P.L. 110-315).

According to AACN (2010), the major barriers to increasing student capacity in nursing schools are insufficient numbers of faculty, admission seats, clinical sites, classroom space, clinical preceptors, and budget constraints. The *Capacity for Nursing Students and Faculty Program*, a section of the *Higher Education Opportunity Act of 2008*, offers capitation grants (formula grants based on the number of students enrolled/or matriculated) to nursing schools allowing them to increase the number of students. **AACN respectfully requests \$50 million for this program in FY 2011.**

Conclusion

AACN acknowledges the fiscal challenges within which the Subcommittee and the entire Congress must work. However, the Title VIII authorities provide a dedicated, long-term vision for educating the new nursing workforce and the next cadre of nurse faculty. The National Institute of Nursing Research invests in developing the scientific basis for quality nursing care. The *Capacity for Nursing Students and Faculty Program* will allow schools to increase student capacity. To be effective these programs must receive additional funding. **AACN respectfully requests \$267.3 million for Title VIII programs, \$160 million for NINR, and \$50 million for the Capacity for Nursing Students and Faculty Program in FY 2011.** Additional funding for these programs will assist schools of nursing to expand their educational and research programs, educate more nurse faculty, increase the number of practicing RNs, and ultimately improve the patient care provided in our healthcare system.



AMERICAN ASSOCIATION OF
COLLEGES OF OSTEOPATHIC MEDICINE

**Testimony of Stephen C. Shannon, DO, MPH
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**Concerning Department of Health and Human Services Appropriations for
Fiscal Year 2011
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
House Committee on Appropriations
Submitted for the Record
April 16, 2010**

On behalf of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to submit this testimony in support of increased funding in fiscal year (FY) 2011 for programs at the Health Resources Services Administration (HRSA), the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ). AACOM represents the administrations, faculty, and students of the nation's 26 colleges of osteopathic medicine and three branch campuses that offer the doctor of osteopathic medicine degree. Today, more than 18,000 students are enrolled in osteopathic medical schools. Nearly one in five U.S. medical students is training to be an osteopathic physician, a ratio that is expected to grow to one in four by 2019.

Title VII

The health professions education programs, authorized under Title VII of the Public Health Service Act and administered through the HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the health care workforce, acting as an essential part of the health care safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII and Title VIII nurse education programs are the only federal programs designed to train clinicians in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

According to HRSA, an additional 30,000 health practitioners are needed to alleviate existing health professional shortages. Combined with faculty shortages across health professions disciplines, racial and ethnic disparities in health care, and a growing, aging population, the anticipated demand for access to care once 32 million more Americans have health insurance as a result of health care reform will strain an already fragile health care system. While AACOM appreciates the investments that this Subcommittee has made in these programs, it recommends increasing funding to \$330 million in FY 2011 for the Title VII programs. Investment in these

programs, including the Training in Primary Care Medicine Program, the Health Careers Opportunity Program, and the Centers of Excellence, is necessary to address the primary care workforce shortage. Strengthening the workforce has been recognized as a national priority, and the investment in these programs recommended by AACOM will help sustain the health workforce expansion supported by the American Recovery and Reinvestment Act (ARRA) and necessitated by the demand for a well trained, diverse workforce that this country will experience as a result of health care reform.

National Health Service Corps

AACOM applauds Congress for increasing the authorization to \$414 million in FY 2011 for the National Health Service Corps (NHSC) through direct appropriations and including the authorized Community Health Center Fund (CHC Fund), which also covers the NHSC, in the Patient Protection and Affordable Care Act. Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. Through scholarships and loan repayment, NHSC supports the recruitment and retention of primary care clinicians to practice in underserved communities. At a field strength of 4,760 in FY 2009, the NHSC still fell more than 24,000 practitioners short of fulfilling the need for primary care, dental, and mental health practitioners in federally-designated Health Professions Shortage Areas (HPSAs), as estimated by HRSA. Growth in HRSA's Community Health Center Program must be complemented with increases in the recruitment and retention of primary care clinicians to ensure adequate staffing, which the NHSC provides. ARRA funding for the NHSC has been vital in this regard, and additional investment will be necessary to sustain the progress as the ARRA funding period ends. AACOM supports the President's budget request of \$169 million for the NHSC program in FY 2011, which would be sufficient to trigger the release of dollars from the CHC Fund. AACOM further recommends that the Subcommittee include report language directing the Secretary to provide enhanced funding for the NHSC, as required under the Patient Protection and Affordable Care Act.

Medical School Development

The President's FY 2011 budget request included \$100 million for the development of new medical schools in HPSAs. The grant program would be administered by HRSA. The budget projected that these funds would support approximately 20 grants for new academic health centers to provide training and research in community-oriented settings. The goal is to increase clinical training in HPSAs as well as to increase the number of new providers who go on to practice in these underserved areas. AACOM supports the appropriation of these funds at a time when it is critical to support the training of new medical students in order to ensure that Americans have access to care.

National Institutes of Health

Research funded by the NIH leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases as well as disease prevention. These efforts improve our nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM recommends \$35 billion in FY 2011 for the NIH.

In today's increasingly demanding and evolving medical curriculum, there is a critical need for more research geared toward evidence-based osteopathic medicine. AACOM believes that it is

vitaly important to maintain and increase funding for biomedical and clinical research in a variety of areas related to osteopathic principles and practice, including osteopathic manipulative medicine and comparative effectiveness. In this regard, AACOM encourages support for the NIH's National Center for Complementary and Alternative Medicine to continue fulfilling this essential research role.

Agency for Healthcare Research and Quality

The AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our nation's health and health care. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years, as well as the funding provided to AHRQ in the ARRA, will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence. More investment is needed, however, to fulfill AHRQ's mission and broader research agenda, especially research in patient safety and prevention and care management research. AACOM recommends \$611 million in FY 2011 for AHRQ, as requested by the President. This investment will preserve AHRQ's current programs while helping to restore its critical health care safety, quality, and efficiency initiatives.

AACOM greatly appreciates the support of the Subcommittee for these funding priorities in an ever increasing competitive environment and is grateful for the opportunity to submit its views. AACOM looks forward to continuing to work with the Subcommittee on these important matters.

The American Association of Colleges of Pharmacy
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United States House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, and Education

Public Witness Testimony for the Record
Regarding FY 2011 funding levels for programs within the U.S. Department of Health and Human Services of interest to U.S. colleges and schools of pharmacy

AACP and its member colleges and schools of pharmacy appreciate the continued support of the U.S. House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, and Education. Our nation's 116 accredited colleges and schools of pharmacy are engaged in a wide-range of programs supported by grants and funding administered through the agencies of the Department of Health and Human Services (HHS). We also understand the difficult task you face annually in your deliberations to do the most good for the nation and remain fiscally responsible to the same. AACP respectfully offers the following recommendations for your consideration as you undertake your deliberations.

US DEPARTMENT OF HEALTH AND HUMAN SERVICES SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS OF PHARMACY

Agency for Healthcare Research and Quality (AHRQ)

AACP supports the Friends of AHRQ recommendation of \$611 million for AHRQ programs in FY11. Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). Academic pharmacy researchers are working to develop a sustainable health services research effort among faculty with AHRQ grant support. As partners in the AHRQ Effective Healthcare programs (CERTs, DeCIDE), pharmacy faculty researchers improve the effectiveness of healthcare services. Some of this research will take place through the development of practice-based research networks focused on improving the medication use process.

- Researchers, including faculty at the University of Illinois, Chicago School of Pharmacy, supported through an AHRQ DEcIDE Network contract determined that a specific drug triad regularly prescribed to patients suffering from chronic obstructive pulmonary disease reduced the risk of death. Researchers determined that other drug combinations increased the risk of death. This research was published in the Archives of Internal Medicine allowing for ready translation of this life-saving knowledge into practice. AHRQ Contract Number 290-05-0038
- Pharmacy faculty researchers at the University of Iowa, supported by AHRQ grant HS018353-01, will seek to improve the quality of medication therapy management programs (MTM) which is a mandated service of the Medicare Part D benefit. This research will provide additional guidance to CMS, PDPs, and other payers and organizations interested in improving the quality of care provided to patients in regard to their medications.

Centers for Disease Control and Prevention (CDC)

AACP supports the CDC Coalition recommendation of \$8.8 billion for CDC core programs in FY11. The educational outcomes of a pharmacist's education include those related to public health. When in community-based positions, pharmacists are frequently providers of first contact. The opportunity to identify potential public health threats through regular interaction with patients provides public health agencies such as the CDC with on-the-ground epidemiologists. Pharmacists support the public health system through the risk

CDC (cont.)

identification of patients seeking medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research in areas such as immunization delivery, integration of pharmacogenetics in the pharmacy curriculum and inclusion of pharmacists in emergency preparedness. Information from the National Center for Health Statistics (NCHS) is essential for faculty engaged in health services research and for the professional education of the pharmacist.

- Researchers at the University of Mississippi School of Pharmacy will be supported in their work to develop and test new malaria drugs by CDC grant [3U01CI000211-05S1](#).

Health Resources and Services Administration (HRSA)

AACP supports the Friends of HRSA recommendation of \$8.5 billion for FY11.

HRSA is a federal agency with a wide-range of policy and service components. Faculty at colleges and schools of pharmacy are integral to the success of many of these. Colleges and schools of pharmacy are the administrative units for interprofessional and community-based linkages programs including geriatric education centers and area health education centers. Pharmacy faculty are supported in their research efforts regarding rural health issues through the Office of Rural Health Policy. Pharmacy students benefit from diversity program funding including Scholarships for Disadvantaged Students.

Office of Pharmacy Affairs

AACP recommends a program funding of \$5 million for FY11 for the Office of Pharmacy Affairs.

AACP member institutions are actively engaged in Office of Pharmacy Affairs (OPA) efforts to improve the quality of care for patients in federally-qualified health centers and entities eligible to participate in the 340B drug discount program. The success of the HRSA Patient Safety and Clinical Pharmacy Collaborative is a direct result of past OPA actions linking colleges and schools of pharmacy with federally-qualified health centers. www.hrsa.gov/patientsafety The result of these links has been the establishment of medical homes that improve health outcomes for underserved and disadvantaged patients through the integration of clinical pharmacy services. The Office of Pharmacy Affairs would benefit from a direct line-item appropriation so that public-private partnerships aimed at improving the quality of care provided at federally qualified health centers can be sustained and expanded.

Poison Control Centers

Colleges and schools of pharmacy are supported by HRSA grant funding for the operation of nine of the 42 poison control centers administered by HRSA.

- Jill E. Michels, faculty member from the University of South Carolina – South Carolina College of Pharmacy (USC), and the Palmetto Poison Center (PPC) were awarded a \$310,000 grant from HRSA. The PPC is housed at the College of Pharmacy and serves all 46 counties in South Carolina receiving over 37,000 calls per year for information and advice. The PPC provides services free-of-charge to the public and health professionals 24 hours-a-day, 365 days-a-year. A recent USC study found that for every dollar spent on the Palmetto Poison Center, more than \$7 were saved in unnecessary healthcare costs, including emergency room and physician visits, ambulance services, and unnecessary medical treatments. <http://poison.sc.edu/about.html>

Bureau of Health Professions (BHPr)

AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of \$600 million for Title VII and VIII programs in FY11.

AACP member institutions are active participants in BHPr programs. Two colleges of pharmacy are current grantees in the Centers of Excellence program (Xavier University -Louisiana, University of Montana). This program focuses on increasing the number of underserved individuals attending health professions institutions. Colleges and schools of pharmacy are also part of Title VII interprofessional and community-based linkages programs including Geriatric Education Centers and Area Health Education Centers. These programs are essential for creating the educational approaches necessary for the Institute of Medicine's recommendations of improving quality through team-based, patient-centered care.

Office of Telehealth Advancement

Technology is an important component for improving healthcare quality and maintaining or increasing access to care. Colleges and schools of pharmacy utilize technology to increase the reach of education to aspiring and current professionals.

- The University of Arizona is supported by a HRSA telehealth grant. "The health will include a state-of-the-art learning center designed for contextual-based learning by interdisciplinary teams of students of various healthcare professions including medicine, nursing and pharmacy. Curricula will be developed to take advantage of both on-site and extramural telemedicine patients. Distance education will also be provided to clinical sites." <http://www.telemedicine.arizona.edu/>
- North Dakota State University College of Pharmacy, Nursing, and Allied Sciences uses grant funding to maintain access to pharmacy services in rural, underserved areas of North Dakota. This program helps over 40,000 rural citizens maintain access to pharmacy services and also supports rural hospital pharmacies. http://hrsa.gov/telehealth/grantedirectory/overview_nd.htm

Food and Drug Administration (FDA)

AACP recommends a funding level of \$3.7 billion for FDA programs in FY11.

Academic pharmacy is working with the FDA to fulfill its strategic goals and the responsibilities assigned to the agency through the Food and Drug Administration Amendments Act. The FDA sees the colleges and schools of pharmacy as essential partners in assuring the public has access to a healthcare professional well versed in the science of safety. Pharmacy faculty and students provide the FDA with a "go-to" group to create the educational outcomes that will empower patients to be members of the healthcare team. The FDA also supports pharmacy schools working to improve the drug manufacturing process.

- Carole L. Kimberlin, a professor, and Almut G. Winterstein, an assistant professor at the University of Florida College of Pharmacy Department of Pharmaceutical Outcomes and Policy, received a one-year \$184,229 award from the Food and Drug Administration to conduct an evaluation of Consumer Medication Information leaflets on selected prescription medications from community pharmacies throughout the United States.
- Thomas C. Dowling's research, "Evaluation of Biopharmaceutics Classification System Class 3 Drugs for Possible Biowaivers," is supported by an FDA grant.

National Institutes of Health (NIH)

AACP supports the Ad Hoc Group for Medical Research recommendation of \$35 billion for FY11.

Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the research spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In 2009, pharmacy faculty researchers received more than \$320 million in grant support from the NIH. AACP member institutions are concerned, as are other health professions education organizations, of the need to increase the number of biomedical researchers. This concern is supported by an initial grant funding success rate that has never been more than 30 percent in the last decade. <http://report.nih.gov/NIHDataBook/Charts/SlideGen.aspx?chartId=126&catId=13>

- Dr. Rueben A. Gonzales, professor of pharmacology and toxicology at The University of Texas at Austin College of Pharmacy, has been awarded a \$2.8 million MERIT Award from the National Institute on Alcohol Abuse and Alcoholism (NIAAA). Gonzales' research involves chemical changes in the brain that underlie alcohol drinking. Of particular interest is the role of dopamine, a chemical produced and found in the brain that relays, amplifies or modulates signals between a neuron and another cell.
- Dr. Stefan Balaz, chair and professor of pharmaceutical sciences at the Albany College of Pharmacy and Health Sciences Vermont campus, has been awarded a five-year grant from the National Institutes of Health (NIH) in the amount of \$1,350,000. Dr. Balaz and his team will develop an approach that will model how chemicals are transported and accumulate in biological membranes, helping researchers predict how new drug candidates are likely to behave in the body.

NIH (cont.)

- The National Institutes of Health has awarded a competitive grant of more than \$777,000 to the University of Maryland School of Pharmacy and Johns Hopkins University researchers to study the costs, risks and benefits of treatments for blood disorders that affect more than 10,000 elderly patients each year. The challenge grant targets a widely accepted practice by clinicians of controlling anemia of myelodysplastic syndromes (MDS), sometimes called pre-leukemias, with erythropoietin, a hormone-controlling red blood cell production.
- A new study by University of Houston College of Pharmacy (UHCOP) researchers suggests that long-term endurance exercise may slow the progression of Parkinson's disease by protecting key cells involved in maintaining function and movement. The research by UHCOP pharmacology graduate student Gaurav Patki and Dr. Yuen-Sum "Vincent" Lau was one of only 12 presentations, out of a pool of nearly 16,000 submissions, to be selected for a news conference at Neuroscience 2009, the annual meeting of the Society for Neuroscience in October 2009. The research was supported by a grant by the National Institute for Neurological Disease and Stroke.

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United States House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, and Education

Public Witness Testimony for the Record
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US DEPARTMENT OF EDUCATION SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS OF PHARMACY

AACP supports the recommendation of the Student Aid Alliance that the:

1. Perkins Loan Program Federal Capital Contribution should be increased to the newly reauthorized level of \$300 million and loan cancellations should be increased to \$125 million.
2. Pell Grant maximum be increased to \$5710.
3. Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP) should be increased to the authorized level of \$400 million.
4. Graduate level programs should be increased to \$126 million.

AACP recommends a funding level of \$160 million for the Fund for the Improvement of Post Secondary Education (FIPSE).

The Department of Education supports the education of healthcare professionals by:

- assuring access to education through student financial aid programs;
- supporting educational research allows faculty to determine improvements in educational approaches; and
- maintaining the quality of higher education through the approval of accrediting agencies.

AACP actively supports increased funding for undergraduate student financial assistance programs. Admission into the pharmacy professional degree program requires at least two years of undergraduate preparation. Student financial assistance programs are essential to assuring colleges and schools of pharmacy are accessible to qualified students. Likewise, financial assistance programs that support graduate education are an important component of creating the next generation of scientists and educators that both our nation and higher education depend on.

**Testimony of John R. Schreiber, M.D., M.P.H., The American Association of Immunologists,
Submitted to the House Appropriations Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies, Regarding the Fiscal Year (FY) 2011 Budget
for the National Institutes of Health – April 12, 2010**

[John R. Schreiber, M.D., M.P.H.: (617) 636-8031; jschreiber@tuftsmedicalcenter.org]

The American Association of Immunologists (AAI), a not-for-profit professional association representing more than 6,500 of the world's leading experts on the immune system, appreciates having this opportunity to submit testimony regarding Fiscal Year (FY) 2011 appropriations for the National Institutes of Health (NIH). The vast majority of AAI members - research scientists and physicians who work in academia, government, and industry - depend on NIH funding to advance their work and the field of immunology.¹ With more than 80% of the \$30.5 billion NIH budget awarded to scientists in communities throughout the United States and collaborating around the world, and with 10% supporting nearly 6,000 research scientists at NIH's own laboratories, NIH funding advances not only immunological and biomedical research, but also regional and national economics by creating and supporting skilled, high-tech jobs that are focused on producing new discoveries to improve human health.²

The immune system's wide reach

Influenza, HIV/AIDS, malaria, tuberculosis, salmonella, the common cold, and more – all are infectious diseases that challenge and sometimes overcome the defenses mounted by the immune system. Chronic diseases like cancer, diabetes, multiple sclerosis, rheumatoid arthritis, asthma, inflammatory bowel disease, and lupus, are either caused by - or due in large part to - an overactive or underactive immune response.³ The immune system, therefore, plays a crucial role in preserving human health and animal health⁴ and increasingly - in our fast-paced, interconnected world - ensuring both community and global health.⁵

Scientists' discovery of ways to prevent and treat these diseases depends on increased understanding of immunology, a relatively new scientific field whose knowledge has exploded in the past 30-40 years.⁶ Important new challenges require understanding the immune response to: 1) pathogens that threaten to become the next pandemic,⁷ 2) man-made and natural infectious organisms that are potential agents of bioterrorism (including plague, smallpox, and anthrax),⁸ and 3) environmental threats. Basic immunological research is crucial to the development of urgently needed new ways to diagnose and treat these threats.

Recent advances in immunological research

Knowledge of the intricacies of the immune system has led to unprecedented medical advances such as successful organ transplantation, new vaccines, and better treatments. Recent immunological advances may further yield profound improvements for people afflicted with debilitating diseases. One such advance involves lupus, a serious chronic autoimmune disease affecting some 1.5 million Americans.⁹ Exciting recent results from the largest clinical trials yet performed have opened the door for the first new drug for effective lupus treatment in 50 years. These trials show that a new type of therapeutic that inactivates the natural molecule "BLyS" results in substantial disease reduction in lupus patients. Both the discovery of BLyS and the development of novel effective treatments are a product of decades of basic immunology research by scientists supported by NIH and other non-profit organizations.

An advance with international importance was the successful response of the biomedical research community to the 2009 swine flu/H1N1 influenza outbreak. Researchers working against time were able to develop an effective vaccine within four months after the first U.S. case was diagnosed on April 13,

2009.¹⁰ This success depended on years of comprehensive basic research on the immune and viral systems, including the ability to identify the molecular DNA sequence of the virus necessary to produce a vaccine. This provided an excellent “test run” for a future pandemic of even more significant public health concern,¹¹ and demonstrated a successful collaboration among basic and translational scientists, clinical practitioners, and pharmacological companies against an infectious disease pandemic.

Another advance in the area of vaccine development involved the successful use of new and improved technologies to identify all of the human genes stimulated by a vaccine, in this case, the Yellow Fever vaccine.¹² This was the first time scientists could determine how different individuals immunized with the same vaccine responded on a molecular level; this approach will significantly enhance our ability to determine how effective vaccines stimulate protective responses and may lead the way to customize vaccines to be more effective for the individual.

The NIH Budget: Building on a Strong Start

AAI greatly appreciates the strong support of this subcommittee and the Congress for medical research, from doubling the NIH budget (FY 1999 to FY 2003), to passing the FY 2009 and 2010 Appropriations Acts [with NIH increases of 3.2 percent (\$938 million) and 2.3 percent (\$691.8 million)], to including in the “American Recovery and Reinvestment Act of 2009” (“ARRA”) a \$10.4 billion supplemental appropriation for NIH. ARRA’s investment in NIH underscored both the President’s and Congress’s realization that investing in biomedical research would not only improve individual and global health, but also stimulate economic activity and job creation: NIH has estimated that each NIH grant supports, on average, “6 to 7 in-part or full scientific jobs,”¹³ while Families USA, a non-profit consumer advocacy organization, has found that, on average, each \$1 of NIH funding going into a state generates more than twice as much in state economic output.¹⁴

As a result of this generous infusion of funds, NIH has been able to fund many excellent, innovative projects, invest in modernizing and enhancing the nation’s research infrastructure, support needed scientific jobs, and lay the groundwork for breakthroughs in the treatment of human disease. And while AAI - and the biomedical research community - are deeply grateful for this recent influx of funds and support, AAI is concerned that imminent advances may not come to fruition if the FY 2011 appropriations level fails to acknowledge the crucial role that ARRA funding now plays within the NIH budget. The AAI funding recommendation for FY 2011 is premised on that concern and designed to address that future.

AAI Recommendation for NIH Funding for FY 2011: Achieving the President’s Vision

Although President Obama’s proposed FY 2011 budget of \$32.2 billion, a 3.2 percent increase over the regular FY 2010 appropriations level, is a good next step toward achieving the President’s vision that “investments in research will improve and save countless lives for generations to come...¹⁵”, it will not ensure that important ongoing research currently funded by combined regular and supplemental (ARRA) appropriations is not interrupted, suspended, or delayed. **AAI urges the subcommittee to provide NIH with a FY 2011 budget of \$37 billion to preserve ongoing research and to enable NIH to grow modestly** from its 2009 and 2010 program levels of ~\$35 billion.¹⁶ Such a budget would also provide NIH with something most scientists have long sought and urgently need: predictable, sustained funding that stabilizes ongoing research projects and the overall research enterprise,¹⁷ inspiring many of our brightest young students to pursue careers in biomedical research.¹⁸

NIH research priorities for FY 2011

AAI is concerned that the Administration’s proposed budget focuses primarily on large-scale, trans-NIH

initiatives, at the expense of investigator-initiated research, a proven route to success and advancement. In fact, the FY 2011 budget decreases the number of competing Research Project Grants by 199. AAI urges that the budget support the NIH Director's stated commitment to individual investigator-initiated research.

AAI supports the proposed 6 percent increase for the Ruth Kirschstein National Research Service Awards, a long-needed training stipend increase for the young scientists who will be the next generation of research leaders. AAI also supports the President's request for \$300 million for the Global Fund to Fight AIDS, Tuberculosis, and Malaria - infectious diseases which devastate people and communities around the world.

Preserving high quality peer review:

Peer review is at the heart of the many decades of successful biomedical research in the United States. NIH is implementing dramatic changes resulting from its "Peer Review Self-Study;" although NIH intends these changes to improve its internationally respected and highly successful peer review system, AAI has concerns that some of the changes have harmed the peer review system, its reviewers, and its applicants. Although AAI supports NIH's effort to address legitimate problems with the system, AAI believes that independent oversight and evaluation is urgently needed.

The NIH "Common Fund"

AAI is concerned that the proposed increase of \$17.5 million for the NIH "Common Fund" (CF), which supports trans-NIH initiatives, may over-emphasize large-scale, multi-disciplinary initiatives, as compared with entrepreneurial investigator-initiated approaches. Although AAI recognizes the value of interdisciplinary research, the CF should not permit the funding of lesser quality research. Instead, all CF applications should be subject to a transparent and rigorous peer review process like all other funded research grant applications. In addition, AAI recommends that the CF not grow faster than the overall NIH budget so that individual researchers, who drive American scientific advancement, are not marginalized.

NIH operations and oversight

AAI strongly supports the President's request for \$1.525 billion for the NIH Research, Management, and Services account, which supports the management, monitoring, and oversight of all research activities. NIH must have adequate resources to supervise and oversee its increasingly large and complex portfolio.

The "NIH Public Access Policy"

AAI respectfully requests that the subcommittee require NIH to publicly report on the cost of the NIH Public Access Policy ("Policy"), including the cost of implementing the voluntary Policy (May 2, 2005 - January 11, 2008); the mandatory Policy (FY 2009 and FY 2010); and the Policy in FY 2011 (projected cost).¹⁹ AAI believes that the Policy duplicates, at great cost, publications and services which are already provided cost-effectively and well by the private sector. The private sector, including not-for-profit scientific societies, already publishes - and makes publicly available - thousands of scientific journals (and millions of articles) that report cutting-edge research funded by both NIH and other entities. AAI urges that, rather than supporting a government bureaucracy that competes with private publishers, NIH should partner with publishers to enhance public access while addressing publishers' key concerns, including respecting copyright law and ensuring journals' continued ability to provide quality, independent peer review of NIH-funded research.

Conclusion

AAI thanks the subcommittee for its strong support for biomedical research, the NIH, and the biomedical researchers who devote their lives to scientific discovery and the prevention, treatment, and cure of disease.

¹ AAI members receive grants from the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute, the National Institute on Aging, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases, but may also receive grants from other NIH Institutes and Centers.

² NIH funding supports “almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every state and around the world.” See <http://www.nih.gov/about/budget.htm> (2/8/10)

³ The immune system works by recognizing and attacking bacteria and viruses inside the body and by controlling the growth of tumor cells. A healthy immune system can protect its human or animal host from illness or disease either entirely - by destroying the virus, bacterium, or tumor cell - or partially, resulting in a less serious illness. It is also responsible for the rejection response following transplantation of organs or bone marrow. The immune system can also malfunction, causing the body to attack itself, resulting in an “autoimmune” disease, such as Type 1 diabetes, multiple sclerosis, lupus or rheumatoid arthritis.

⁴ Research on the immune system is also of enormous benefit to pets and agricultural livestock as it supports the development of new vaccines and treatments for animal diseases. It also improves our understanding of animal to human transmission (as, for example, with H1N1 influenza (“swine flu”).

⁵ NIH funds research “on ‘neglected infectious diseases’ such as malaria, tuberculosis, and a host of tropical diseases—diseases that are most prevalent in low-income countries, and that are insufficiently researched by the drug industry.” Testimony of Ron Pollack, Executive Director, Families USA, before the House Energy and Commerce Subcommittee on Health, hearing on “Treatments for an Ailing Economy: Protecting Health Care Coverage and Investing in Biomedical Research,” November 13, 2008, page 4.

⁶ Although the first vaccine (against smallpox) was developed in 1798, most of our basic understanding of the immune system has developed in the last 30-40 years, making immunology ripe for new discoveries.

⁷ While research scientists and public health professionals must, of course, respond to emergent threats (such as the current concern related to the H1/N1 flu virus), AAI believes that the best preparation for a pandemic is to focus on basic research to combat seasonal flu, including building capacity, pursuing new production methods (cell based), and seeking optimized flu vaccines and delivery methods.

⁸ To best protect against bioterrorism, scientists should focus on basic research, including working to understand the immune response, identifying new and potentially modified pathogens, and developing tools (including new and more potent vaccines) to protect against these pathogens.

⁹ See <http://www.lupusresearch.org/about/press-room/press-releases/new-study-findings-represent.html>

¹⁰ See <http://www3.niaid.nih.gov/about/directors/pdf/110409NIAIDStatementLHSH1N1.pdf>. On 7/22/09, NIAID reported the launch of clinical trials on two candidate H1N1 vaccines in adults (see <http://www.nih.gov/news/health/jul2009/niaid-22.htm>). On 8/18, NIAID announced it would begin trials in children (see <http://www3.niaid.nih.gov/news/newsreleases/2009/H1N1pedvax.htm>). The Food and Drug Administration approved a vaccine on 9/15; it was made publicly available on 10/5 (see <http://www3.niaid.nih.gov/about/directors/pdf/110409NIAIDStatementLHSH1N1.pdf>).

¹¹ A pandemic can be mild or serious. Seasonal influenza, which may or may not lead to a pandemic, results in ~200,000 hospitalizations and ~36,000 deaths nationwide in an average year. A serious influenza pandemic could result in the hospitalization of nearly 10 million Americans and the death of almost 2 million, at a projected cost of over \$680 billion. (See "Pandemic Influenza: Warning, Children At-Risk," Trust for America's Health, 10/07, <http://healthyamericans.org/reports/fluchildren/KidsPandemicFlu.pdf>)

¹² Published in *Nature Immunology*, Jan. 10, 2009, pp. 116-25, from the laboratory of B. Pulendran.

¹³ Testimony of Raynard S. Kington, M.D., Ph.D., Acting Director, National Institutes of Health, Witness appearing before the House Subcommittee on Labor-HHS-Education Appropriations Subcommittee, March 26, 2009. Dr. Kington was citing the NIH report: "Estimating the Number of Senior/Key Personnel Engaged in NIH Supported Research," NIH study 07-5002-OD-ORIS-OER, issued October 2008.

¹⁴ "In Your Own Backyard: How NIH Funding Helps Your State's Economy," Families USA (June 2008). The report cited numerous other economic benefits of NIH funding, including: FY 2007 NIH funding created and supported more than 350,000 jobs generating wages in excess of \$18 billion, with an average wage of \$52,000 (nearly 25% higher than the average U.S. wage); the amount of new business activity generated in the states ranged from \$8.39 billion to \$13 million, with 14 states generating over \$1 billion each; in 10 states, each NIH dollar generated at least \$2.26 in economic activity; in 6 states, more than 20,000 new jobs were created; and in 7 states, the average wage per new job exceeded \$55k.

¹⁵ See http://www.whitehouse.gov/blog/09/09/30/An_Historic_Commitment_to_Research

¹⁶ After adding 1) an increase reflecting the projected rate of inflation for biomedical research for FY 2011 (3.2%, or \$1.1 billion), and 2) an increase for growth (2.5%), the total increase requested above the FY 2010 program level of \$35 billion is 5.71%.

¹⁷ President Obama has recognized the long-term nature of science and the need for a mutual, long-term commitment by both scientist and government. "Breakthroughs in medical research take far more than the occasional flash of brilliance.... Progress takes time; it takes hard work; it can be unpredictable; it can require a willingness to take risks and going down some blind alleys occasionally -- figuring out what doesn't work is sometimes as important as figuring out what does -- all of this needs the support of government. It holds promise like no other area of human endeavor, but we've got to make a commitment to it." See [http://www.whitehouse.gov/the_press_office/Remarks-by-the-President-on-the-American-Recovery-and-Reinvestment-Act-at-the-National-Institutes-of-Health/\(9/30/09\)](http://www.whitehouse.gov/the_press_office/Remarks-by-the-President-on-the-American-Recovery-and-Reinvestment-Act-at-the-National-Institutes-of-Health/(9/30/09))

¹⁸ As a Presidential candidate, President Obama acknowledged that "Sustained and predictable increases in research funding will allow the United States to ...expand the frontiers of human knowledge... [and] provide greater support for high-risk, high-return research and for young scientists at the beginning of their careers." (See <http://www.sciencedebate2008.com/www/index.php?id=42> (8/30/08).

¹⁹ Costs reported should include all costs incurred by the National Library of Medicine (NLM) and any other NIH Institutes, Centers, or Office, and include a) the number of FTEs and contracted services; b) the cost of personnel and administrative services; c) time spent directly on the promotion, management, enforcement, and assessment of the Policy; and d) all costs associated with network infrastructure improvements including but not limited to bandwidth capabilities, server capacity, and equipment.



Written Statement of
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House Appropriations Subcommittee
 On Labor, Health and Human Services, and Education
 2358B Rayburn House Office Building
 Washington, DC
 April 16, 2010

FY 2011 Appropriations Request Summary

| | <u>FY10 Actual</u> | <u>FY11 Budget</u> | <u>AANA FY 11 Request</u> |
|---|---|---|--|
| HHS / HRSA / BHP: Title VIII Advanced Education Nursing, Nurse Anesthetist Education Reserve | Awaiting grant allocations—in FY09 awards amounted to approx. \$3.5MM | Grant allocations not specified | \$4 MM for nurse anesthesia education |
| Total for Advanced Education Nursing, from Title VIII | \$64.44 MM for Advanced Education Nursing | \$64.44 MM for Advanced Education Nursing | \$76.514 MM for advanced education nursing |
| Title VIII HRSA BHP: Nursing Education Programs | \$243,872,000 | \$243,872,000 | \$267,300,000 |
| CDC/ Division of Healthcare Quality and Promotion | | | \$26 MM |
| HHS /Office of the Secretary | | | \$1 MM |

The American Association of Nurse Anesthetists (AANA) is the professional association for the 44,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists practicing today, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 32 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some states are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and

the offices of dentists, podiatrists and plastic surgeons. Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety in the field of anesthesia was bolstered by the Institute of Medicine report in 2000, which found that anesthesia is 50 times safer than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington DC, 2000.) Nurse anesthetists continue to set for themselves the most rigorous continuing education and re-certification requirements in the field of anesthesia. Relative anesthesia patient safety outcomes are comparable among nurse anesthetists and anesthesiologists, with Pine having concluded, “the type of anesthesia provider does not affect inpatient surgical mortality.” (Pine, Michael MD et al. “Surgical mortality and type of anesthesia provider.” *Journal of American Association of Nurse Anesthetists*. Vol. 71, No. 2, p. 109 – 116. April 2003.)

Even more recently, a study published in *Nursing Research* indicates that obstetrical anesthesia, whether provided by CRNAs or anesthesiologists, is extremely safe, and there is no difference in safety between hospitals that use only CRNAs compared with those that use only anesthesiologists. (Simonson, Daniel C et al. “Anesthesia Staffing and Anesthetic Complications During Cesarean Delivery: A Retrospective Analysis.” *Nursing Research*, Vol. 56, No. 1, pp. 9-17. January/February 2007). In addition, a recent AANA workforce study showed that CRNAs and anesthesiologists are substitutes in the production of surgeries. Through continual improvements in research, education, and practice, nurse anesthetists are vigilant in our efforts to ensure patient safety.

CRNAs provide the lion’s share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves. For decades, CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live.

Importance of Title VIII Nurse Anesthesia Education Funding

The nurse anesthesia profession’s chief request of the Subcommittee is for \$4 million to be reserved for nurse anesthesia education and \$76.514 million for advanced education nursing from the Title VIII program. We feel that this funding request is well justified, as we are seeing a vacancy rate of nurse anesthetists in the U.S. that is impacting the public’s access to healthcare. The Title VIII program, which has been strongly supported by members of this Subcommittee in the past, is an effective means to help address the nurse anesthesia workforce demand.

Increasing funding for advanced education nursing from \$64.44 million to \$76.514 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S. The program provides for competitive grants that help enhance advanced nursing education and practice and traineeships for individuals in advanced nursing education programs. This funding is critical to meet the nursing workforce needs of Americans who require healthcare, particularly as we see more patients enter the system with the successful passage of health reform. More APRNs will be needed to fill the gap to ensure access to care. In addition, this funding provides a two-fold benefit for the nurse workforce. It not only seeks to increase the number of providers in rural and underserved America but also prepares providers at the master’s and doctoral levels, increasing the number of clinicians who are eligible to serve as faculty.

There continues to be high demand for CRNA workforce in clinical and educational settings. In 2007, an AANA nurse anesthesia workforce study found a 12.6% vacancy rate in hospitals for CRNAs, and a 12.5% faculty vacancy rate. The supply of clinical providers has increased in

recent years, stimulated by increases in the number of CRNAs trained. Between 2000-2009, the number of nurse anesthesia educational program graduates doubled, with the Council on Certification of Nurse Anesthetists (CCNA) reporting 1,075 graduates in 2000 and 2,239 graduates in 2009. This growth is leveling off somewhat, but is expected to continue. However, even though the number of graduates has doubled in eight years, the nurse anesthetist vacancy rate remained steady at around 12%, which is likely due to increased demand for anesthesia services as the population ages, growth in the number of clinical sites requiring anesthesia services, and CRNA retirements.

The problem is not that our 108 accredited programs of nurse anesthesia are failing to attract qualified applicants. It is that they have to turn them away by the hundreds. The capacity of nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least one year serving in an acute care healthcare practice environment. Nurse anesthesia educational programs are located all across the country, including Alabama, California, Connecticut, Illinois, Kansas, Louisiana, Minnesota, New York, Ohio, Rhode Island, Virginia, and Wisconsin.

Recognizing the important role nurse anesthetists play in providing quality healthcare, the AANA has been working with the 108 accredited nurse anesthesia educational programs to increase the number of qualified graduates. In addition, the AANA has worked with nursing and allied health deans to develop new CRNA programs. To truly meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow. With the help of competitively awarded grants supported by Title VIII funding, the nurse anesthesia profession is making significant progress, expanding both the number of clinical practice sites and the number of graduates.

The AANA is pleased to report that this progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. As mentioned earlier, the study by Pine et al confirms, "the type of anesthesia provider does not affect inpatient surgical mortality." Yet, for what it costs to educate one anesthesiologist, several CRNAs may be educated to provide the same service with the same optimum level of safety. Nurse anesthesia education represents a significant educational cost-benefit for supporting CRNA educational programs with federal dollars vs. supporting other, more costly, models of anesthesia education.

To further demonstrate the effectiveness of the Title VIII investment in nurse anesthesia education, the AANA surveyed its CRNA program directors to gauge the impact of the Title VIII funding. Of the eleven schools that had reported receiving competitive Title VIII Nurse Education and Practice Grants funding from 1998 to 2003, the programs indicated an average increase of at least 15 CRNAs graduated per year. They also reported on average more than doubling their number of graduates. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas.

We believe it is important for the Subcommittee to allocate \$4 million for nurse anesthesia education for several reasons. First, as this testimony has documented, the funding is cost-

effective and needed. Second, this particular funding is important because nurse anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. Third, this funding meets an overall objective to increase access to quality healthcare in medically underserved America.

Title VIII Funding for Strengthening the Nursing Workforce

The AANA joins The Nursing Community and the Americans for Nursing Shortage Relief (ANSR) Alliance in support of the Subcommittee providing a total of \$267.3 million in FY 2011 for nursing shortage relief through Title VIII. This amount is a modest 10 percent increase over FY 2010 levels and necessary in a time of expanded access through health reform. As more patients enter the system, it's imperative there are enough nurses to care for them. AANA asks that of the \$267.3 million, \$76.514 million go to Advanced Education Nursing to help increase clinicians in underserved communities and those eligible to serve as faculty. The AANA appreciates the support for nurse education funding in FY 2010 and past fiscal years from this Subcommittee and from the Congress.

In the interest of patients past and present, particularly those in rural and medically underserved parts of this country, we ask Congress to invest in CRNA and nursing educational funding programs and to provide these programs the sustained increases required to help ensure Americans get the healthcare that they need and deserve. Quality anesthesia care provided by CRNAs saves lives, promotes quality of life, and makes fiscal sense. This federal support for Title VIII and advanced education nurses will improve patient access to quality services and strengthen the nation's healthcare delivery system.

Safe Injection Practices

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects of the Safe Injection Practices Coalition, intended to reduce and eventually eliminate the incidence of healthcare facility acquired infections. In the interest of promoting safe injection practice, and reducing the incidence of healthcare facility acquired infections, we recommend the Committee provide the following appropriations for FY 2011:

- \$26 million for the Centers for Disease Control and Prevention's (CDC) Division of Healthcare Quality and Promotion to address outbreaks and promote innovative ways to adhere to injection safety and infection control guidelines. \$5 million would be used to support the CDC's efforts around provider education and patient awareness activities; and
- \$1 million for the Department of Health and Human Services (HHS) to expand its current focus for reducing healthcare acquired infections (HAIs) from hospitals to outpatient settings with the development of an action plan to reduce HAIs in outpatient settings with a specific focus on injection safety.

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Introduction

The National Institutes of Health (NIH) is the world's leader in medical discoveries that improve people's health and save lives. NIH-funded scientists at universities and research centers throughout the nation investigate ways to prevent, treat, and even cure the complex diseases of the brain. Because there is much work still to be done, the American Brain Coalition writes to ask for the House Appropriations Committee's continued support for increased biomedical research funding at NIH.

The American Brain Coalition

The American Brain Coalition (ABC) is a nonprofit organization that seeks to reduce the burden of brain disorders and advance the understanding of the functions of the brain. The ABC, made up of over 50 member organizations, brings together afflicted patients, the families of those that suffer, the caregivers, and the professionals that research and treat diseases of the brain.

The brain is the center of human existence, and the most complex living structure known. As such, there are thousands of brain diseases from Rett Syndrome and autism to mental illness and Parkinson's disease. The American Brain Coalition, unlike any other organization, brings together people affected by *all* diseases of the brain.

The ABC is working to raise public awareness and support for diseases of the brain. Fifty million Americans – our relatives, friends, neighbors, and your constituents – are affected by diseases of the brain. This number does not include the millions more family members whose lives are affected as they care for those who suffer. Our goal is to be a united voice for these patients, and to work with Congress and the Administration to alleviate the burden of brain disease. A large part of that goal involves support for NIH research.

Thank You for Your Support

The American Brain Coalition would like to thank the Members of this Subcommittee and the House for its support for the \$10 billion provided to the National Institutes of Health in the 2009 economic stimulus package. This funding provided the opportunity for a substantial number of two-year research grants and infrastructure projects in every state of the nation to move forward and enhance our understanding of an array of physical and mental health concerns.

Progress in the fields of addiction, alcoholism, Parkinson's disease and stroke has already been made by scientists funded through ARRA funding. One such investigator is studying how to improve motor function following stroke. Another investigator is using specially-designed video games to understand the cognitive effects of autism, in order to develop behavioral or drug treatments. Please visit <http://bit.ly/a0g8aA> to learn more about the progress made.

Over 1,900 new investigators received ARRA grant funding. Scientists were inspired to do more research and patients suffering from debilitating neurological and psychiatric disorders were given hope, thanks to your generous support of ARRA.

Congressional Support Accelerates Discovery

In the late 1990s, Congress made a commitment to double the budget of the National Institutes of Health (NIH) over the course of five years. The primary goal for the added funds was to discover better treatments and cures for human disease. Congress delivered on its promise, and scientists have amassed a wealth of medical knowledge. Today, researchers have a greater understanding of how the brain and nervous system function due to NIH-funded research.

Many recent scientific discoveries, including those in neurology, psychiatry, and behavioral research have begun to show their potential. Insights into the biology of schizophrenia, epilepsy, Alzheimer's, and other disorders have led to the development of enhanced diagnostic techniques, better prevention methods, and more effective treatments. Simply put: the result of Congressional support for research leads to improved patient care.

Today's Research: Hope for the Future

Today's research is the foundation for future breakthroughs. The federal government's investment in research must be sustained in order to translate today's scientific findings into further bedside treatments, and the ABC supports NIH in its entirety. Recent discoveries, such as those listed below, are a direct result of robust funding for the NIH.

- The development of drugs that reduce the severity of symptoms for those suffering with multiple sclerosis and Parkinson's disease
- The identification of stroke treatment and prevention methods
- The discovery of a new class of anti-depressants that produce fewer side effects than their predecessors
- The creation of new drugs to help prevent epileptic seizures
- The expansion of treatments for the psychotic symptoms of schizophrenia

My own field of research concerns schizophrenia, a devastating brain disorder that affects 1% of the population but is the seventh most costly medical illness to our society because of its life-long disability. Basic brain research funded by the National Institute of Mental Health has transformed our understanding of the disorder and illuminated new targets for therapeutic intervention that affect symptoms untouched by existing drugs.

Research Improves Health and Fuels the Economy

Diseases of the nervous system pose a significant public health and economic challenge, affecting nearly one in three Americans at some point in life. Improved health outcomes and positive economic data support the assertion that biomedical research is needed to improve public health today and save money tomorrow.

Not only does research save lives and fuel today's economy, it is also a wise investment in the future. For example, 5 million Americans suffer from Alzheimer's disease today, and the cost of caring for these people is staggering. Medicare expenditures are \$91 billion each year, and the cost to American businesses exceeds \$60 billion annually, including lost productivity of employees who are caregivers. As the baby boom generation ages and the cost of medical services increases, these figures will only grow. Treatments that could delay the onset and progression of the disease by even five years could save \$50 billion in healthcare costs each year. Research funded by the NIH is critical for the development of such treatments. The cost of investing in NIH today is minor compared to both current and future healthcare costs.

Additionally, it is estimated that each billion of dollars of NIH funding generates 15,000 to 20,000 well-paying jobs that can't be sent offshore. Science funding also generates more than twice as much in state and local economic output. A strong federal investment in research can assist your state in maintaining a biomedical research foundation that attracts companies and investors. For instance, in FY2007, NIH dollars generated more than \$50 billion in new state business.

Strong science funding can bolster the economy today and improve our nation's long term health and competitiveness tomorrow. Robust research and development investment remains the key to America's long-term global competitiveness. NIH funding serves as the basis for future innovation and industries such as pharmaceutical, medical device, and biotechnology.

FY 2011 Recommendation

The American Brain Coalition supports \$35 billion for the National Institutes of Health in FY 2011. This represents the new functional capacity funded by the annual appropriations process and the American Recovery and Reinvestment Act. In addition, it will help the NIH to achieve its broad research goals and provide hope for the millions of Americans affected with neurological and psychiatric disorders, while strengthening the economy and creating jobs throughout the country.

There is still much work to be done to uncover the mysteries of the brain. FY 2011 provides Congress with the opportunity to renew its past commitment to health funding as a national priority.

American College of Cardiology**Public Witness Testimony for the Record to the****Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations**

The American College of Cardiology (ACC) appreciates the opportunity to provide the subcommittee with recommendations for Fiscal Year 2011 (FY 11) funding for cardiovascular research and prevention. The ACC is a more than 38,000 member, non-profit professional medical society and teaching institution whose mission is to advocate for quality cardiovascular care—through education, research promotion, development and application of standards and guidelines—and to influence health care policy.

Heart disease is America's number one killer and a major cause of permanent disability. Nearly 1 in 3 adults in the United States (US) suffers from heart disease. Heart disease and stroke will cost the United States an estimated \$503.2 billion in 2010, including health care costs and lost productivity.

The death rates attributable to cardiovascular disease actually have declined due to advances in science through diagnostic tests, drug and device therapies, surgical innovations, enhanced emphasis on prevention, and innovative public education programs. Federal research provided for many of these advances that improve understanding of the prevention and treatment of cardiovascular disease, leading to better outcomes and increased quality of life for patients.

ACC Funding Recommendations for FY11

As the subcommittee considers its appropriations for programs within the Department of Health and Human Services, the ACC urges support of the following recommendations.

National Institutes of Health (NIH)

The ACC supports an appropriation of \$35.2 billion for the National Institutes of Health (NIH). This funding level will allow the NIH to build on momentum achieved from investments from the American Recovery and Reinvestment Act (ARRA). The NIH currently invests only four percent of its budget on heart research; the ACC urges NIH to invest a higher percentage of its budget to heart research.

National Heart, Lung, and Blood Institute (NHLBI)

The ACC supports an appropriation of \$3.514 billion for the National Heart, Lung, and Blood Institute (NHLBI). The NHLBI does critical research into the causes, diagnosis, and treatment of heart disease.

Agency for Healthcare Research and Quality (AHRQ)

The ACC supports the President's budget request of \$611 million for the Agency for Healthcare Research and Quality (AHRQ). The ACC supports the recent increases in funding for AHRQ's comparative effectiveness research program, and also believes AHRQ's health services research related to health care costs, quality, and access are critically important.

CDC Heart Disease and Stroke Prevention

The ACC supports an appropriation of \$76.221 million for the Centers for Disease Control and Prevention (CDC) Division for Heart Disease and Stroke Prevention. These public education efforts are helping to reduce blood pressure and cholesterol, educate about heart disease and stroke signs and symptoms, enhance emergency response and quality care, and end treatment disparities.

The ACC also supports an appropriation of \$37.087 million for CDC's WISEWOMAN program. This program screens uninsured and under-insured low-income women ages 40 to 64 for heart disease and stroke risk and those with abnormal results receive counseling, education, referral and follow up.

HRSA Rural and Community AED Program

The ACC supports an appropriation of \$8.927 million for the Health Resources and Services Administration (HRSA) Rural and Community Access to Emergency Devices Program, which would restore it to its FY 2005 level when 47 states received resources from the initiative. This program provides competitively awarded grants to states to purchase automated external defibrillators (AEDs), train lay rescuers and first responders in their use, and place them in public areas where sudden cardiac arrests are likely to occur. In 2009 only ten states received funding for this initiative.

NHLBI and CDC: Congenital Heart Disease Research and Surveillance

The ACC is pleased that the recently enacted "Patient Protection and Affordable Care Act" includes provisions to enhance and expand the infrastructure to track the epidemiology of congenital heart disease (CHD) and to conduct and support research on it. The ACC as well as the Adult Congenital Heart Association, Mended Little Hearts and Children's Heart Foundation, stand ready to work with the subcommittee to advance these policies.

Congenital heart defects are the most common birth defect in the US and are a leading cause of child mortality. The success of childhood cardiac intervention has created a new chronic disease – CHD. Those who receive successful intervention will need life-long special cardiac care and face high rates of heart failure, rhythm disorders, stroke and sudden cardiac death. Thanks to the increase in survival, the CHD population is rising by 5 percent a year; there are about 800,000 children and 1 million adults in the US now living with CHD.

Despite the prevalence and seriousness of the disease, data collection and research are limited. Federal funding support for CHD surveillance through CDC and research through NHLBI is necessary to help prevent premature death and disability in this rapidly-growing and severely underserved population.

Cardiovascular Disease Research Gaps

As the healthcare system evolves towards better integration of health information technology (HIT), clinical decision support tools, and performance measurement, the need for meaningful clinical practice guidelines is essential. The American College of Cardiology Foundation (ACCF) and the American Heart Association (AHA) have a long history in the development of clinical practice guidelines, and have close to 20 guidelines on a range of cardiovascular topics.

The guidelines are developed through a rigorous, evidence-based methodology, including multiple layers of review and expert interpretation of the evidence on an ongoing, regular basis.

Many clinical research questions remain unanswered or understudied, however. The ACC has identified knowledge gaps for cardiovascular disease that if addressed, have potential to positively impact patient outcomes, costs, and the efficiency of care delivery. A federal investment through the NHLBI and AHRQ to answer the following questions will help to better narrow the target population who can benefit from treatment and therefore increase the efficacy and efficiency of patient-centered care delivery.

1. What is the effect of common cardiovascular therapies on elderly populations whose metabolism and kidney function are lower and may not respond to medications in the same way as the younger patients typically included in clinical trials?
2. What is the effect of common cardiovascular therapies on patients with multiple other diseases/conditions?
3. What is the effect of common cardiovascular therapies on women? What are signs and risk factors for cardiovascular disease in women?
4. What are the best approaches to increasing patient compliance with existing therapies?
5. What screening and risk models (existing or new) could further define who will benefit from various therapies?
6. What are the optimal management strategies for anticoagulation and antiplatelet agents in heart attack patients, patients with stents, and atrial fibrillation patients to maximize benefit and reduce bleeding risks?
7. What are the best approaches to managing complex but understudied cardiovascular topics such as congenital heart disease, valvular heart disease, and hypertrophic cardiomyopathy? These topics have become areas of higher research interest as techniques have developed to extend the lives of patients with these disorders.
8. What are the risks and benefits of common off-label uses of widely used therapies and procedures?
9. What are the risks and benefits of various cardiovascular screening protocols, such as those for imaging methods used to correctly identify patients who will benefit from surgical, endovascular, and/or medical interventions?
10. What are the best catheter-based techniques to increase treatment success and reduce complications for both coronary and cardiac rhythm procedures?
11. What are the effects of nutrition, environment and genetics on the occurrence of congenital heart defects?

The above list of topics is not exhaustive but gives an overview of some of the themes of the evidence gaps that exist across the ACCF/AHA guidelines. In addition to specific clinical research topics, the ACCF recommends funding to help address structural issues that could help identify, prioritize, and interpret research findings over the long term.

1. The NIH and or AHRQ should fund more trials of direct comparison of clinical effectiveness between pharmacological and other therapies. Without these important trials, the current emphasis on promoting comparative effectiveness will be founded upon efficacy trials and not effectiveness.

2. The NHLBI should work with the clinical cardiology community to proactively design clinical trials to address unanswered clinical questions and identify methods that allow for greater comparability among studies. NHLBI should work with ACCF and the AHA to develop an evidence model that would drive future research initiatives based on current evidence gaps in the guidelines; and
3. NIH should fund the development of a robust informatics infrastructure across Institutes to process research evidence. Studies should be designed such that their results could be “fed” into a computer model that would provide additional insights for developers of clinical recommendations.
4. NIH and or AHRQ should fund studies of patient preference and values.

ARRA in Action: Collaborating to Improve Cardiovascular Care

In September 2009, the ACC was pleased to be awarded two federal grants under ARRA. The ACC has applied for three others, in addition to serving as a subcontractor on several other grant applications.

Grand Opportunity Grants

Comparative Effectiveness of PCI versus CABG Grant

The NHLBI awarded a Grand Opportunity grant to the ACC in partnership with the Society of Thoracic Surgeons (STS) to study the comparative effectiveness of the two forms of coronary revascularization; percutaneous coronary intervention (PCI) and coronary artery bypass graft (CABG) surgery (Award Number 1RC2HL10148). Now entering the second half of this two year award period, the study is comparing these two cardiac procedures using existing databases from the ACC and STS, as well as the Centers for Medicare and Medicaid Services 100 percent denominator file data. By linking these three databases, the study will help physicians make better decisions and improve healthcare for patients with coronary artery disease.

National Cardiovascular Research Infrastructure (NCRI) Grant

The NHLBI also awarded a Grand Opportunity grant (Award Number 1RC2HL101512-01) to Duke Clinical Research Institute (DCRI), with the ACC serving as a subcontractor, to develop a clinical investigator network based upon the data collection activities of ACC’s National Cardiovascular Data Registries (NCDR[®]). These registries have previously been used to quantify outcomes and identify gaps in the delivery of quality cardiovascular patient care in the United States. The current grant will extend these existing systems by establishing a National Cardiovascular Research Infrastructure (NCRI) that will unify sites with a centralized clinical research network. NCRI will facilitate interoperable clinical research by enhancing site recruitment, training, performance, and accountability and will create a sustained improvement in the efficiency and quality of the interaction between the clinical research subject, the clinician investigator, the expert guidelines committee, and policymakers.

Prospect Grants #RFA-HS-10-005: Building New Clinical Information for Comparative Effectiveness Research

Valvular Heart Disease Registry Grant Application

In February 2010, ACC and STS again joined forces to submit a grant application entitled “ACCF-STC Database Development and Collaboration on the Comparative Effectiveness of Valvular Heart Disease.” This application was in response to the above announcement from

AHRQ. The DCRI Data Coordinating and Analysis Center collaborated on the development of this grant and, if awarded, would provide the clinical outcomes and analysis for the project. The purpose of this grant would be for ACCF and STS to take advantage of their existing registries to create and maintain a sustainable disease-based, multi-center registry for valvular heart disease (VHD), a robust, efficient system of longitudinal follow-up for registry patients, and to perform a direct comparison of initial clinical outcomes following different management strategies of patients with severe aortic stenosis.

Infrastructure Development for the Comparative Effectiveness of Atrial Fibrillation

In partnership with the Heart Rhythm Society (HRS), ACC submitted a grant to AHRQ proposing to develop the electronic database infrastructure necessary to collect prospective data of patients with atrial fibrillation through use of ACC's NCDR. Once developed, new evidence comparing various interventions will be available by using this new NCDR registry database to better understand the procedures and improve healthcare for patients with atrial fibrillation, one of the most common arrhythmias in clinical practice. Such data will contain process, risk-adjusted outcomes, utilization, provider characteristics, and cost data spanning several years that has a potentially great benefit to society. Specifically, this study will permit comparative effectiveness research of the management of patients with atrial fibrillation, including comparisons across race, gender, and age. These comparisons will be more comprehensive than any currently available, and will be of inestimable benefit in provider decision-making and patient care in a variety of clinical situations.

Enhanced Registries for Quality Improvement and Comparative Effectiveness (AHRQ #RFA-HS-10-020)

Integrating Local EHR Data into the ACC NCDR Registry to Improve Care (LEAN) Grant Application

The aim of this grant application is to develop an informatics solution that captures and delivers real-time clinical patient information to multiple care settings. ACC is collaborating with Yale University School of Medicine, Christiana Care Center for Outcomes Research, Sisters of Mercy Health System, Saint Luke's Hospital of Kansas City-Mid America Heart Institute, and Duke University Medical Center on this important endeavor. The formation of the proposed infrastructure will not only drive quality improvement, but also facilitate comparative effectiveness research. This project aligns particularly well with the goals and purposes expressed nearly two years ago by the ACCF and the NCDR with the launch of the IC³ Registry (renamed the PINNACLE Registry™ in the fall of 2009). PINNACLE was designed to improve the quality of outpatient cardiovascular care by reducing inappropriate variations in care, by eliminating gaps in care, and by improving care coordination for patients with cardiovascular disease. Realization of these objectives will rely on the existence of a strong, unified data collection infrastructure that will allow for retrieval across both inpatient and outpatient care settings, as well as provide quality improvement feedback.

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**Statement for the Record of the American College of Physicians
to the House Appropriations Subcommittee on Labor,
Health and Human Services, Education, and Related Agencies
Re: FY 2011 Budget, Department of Health and Human Services**

April 12, 2010

Chairman Obey and Ranking Member Tiahrt, thank you for allowing me to share the American College of Physicians' (ACP's) views on the Department of Health and Human Services budget for FY2011.

I am Joseph W. Stubbs, MD, FACP, President of the American College of Physicians. I have also had the privilege of serving adult patients for the past 27 years as a full-time internist and geriatrician in a nine-person primary care group practice in Albany, Georgia. Every day, I see where the rubber of health policy meets the road of real patient lives. In my practice, we have more than 50 employees, and I have seen the ratio of physician to staff grow from 1:3 to 1:6 in the last 10 years. Health care in the United States is facing an unprecedented challenge of affordability and sustainability. I am pleased to be able to represent the College.

The American College of Physicians represents 129,000 internal medicine physicians, residents, and medical students. ACP is also the nation's largest medical specialty society and its second largest physician membership organization.

ACP is pleased to urge full funding for the following proven programs that currently receive appropriations from the Subcommittee:

- Title VII, Section 747, Primary Care Training and Enhancement, at no less than \$125 million;
- National Health Service Corps, \$414,095,394 million, in addition to the \$290 million in enhanced funding through the Community Health Fund; and
- Agency for Healthcare Research and Quality, \$611 million.

In addition to fully funding the existing programs noted above, ACP is pleased to support the following new programs, as created in the Patient Protection and Affordable Care Act (PPACA), with the stipulation that they should be fully funded:

- Title VII, Section 747A, Teaching Health Centers, \$50 million;
- Primary Care Training Extension Program, \$120 million;
- National Health Care Workforce Commission;
- State healthcare workforce development grants; and
- State demonstration programs to evaluate alternatives to current medical tort litigation, \$50 million.

We are experiencing a primary care shortage in this country, the likes of which we have not seen. The expected demand for primary care in the United States continues to grow exponentially while the nation's supply of primary care physicians dwindles and interest by U.S. medical graduates in adult primary care specialties steadily declines. With passage of the PPACA, we expect the demand for primary care services to increase with the addition of 32 million Americans receiving access to health insurance, once the law is fully implemented.

A strong primary care infrastructure is an essential part of any high-functioning healthcare system. In this country, primary care physicians provide 52 percent of all ambulatory care visits, 80 percent of patient visits for hypertension, and 69 percent of visits for both chronic obstructive pulmonary disease and diabetes, yet they comprise only one-third of the U.S. physician workforce. Those numbers are compelling, considering that **over 100 studies show primary care is associated with better outcomes and lower costs of care** (http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf).

Many regions of the country are currently experiencing shortages in primary care physicians. The Institute of Medicine (IOM) reports that it would take 16,261 additional primary care physicians to meet the need in currently underserved areas alone. A 2008 study published in Health Affairs projects a shortage of 35,000 to 40,000 or more primary care physicians for adults by 2025 (Colwill JM, Cultice JM, Kruse RL. Will generalist physician supply meet demands of an increasing and aging population? Health Affairs (Millwood). 2008 May-Jun;27(3):w232-41. Epub 2008 Apr 29). With an aging and growing population, family physicians' and general internists' workloads are expected to increase by 29% between 2005 and 2025. To help alleviate the shortage of primary care physicians, we believe sufficient funding should be provided for Title VII programs and the National Health Service Corps.

The health professions education programs, authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA), support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces, and are critical to help institutions and programs respond to the current and emerging challenges of ensuring all Americans have access to appropriate and timely health services.

Within the Title VII program, while we applaud the President's request for \$54 million for the Section 747, Training in Primary Care Medicine and Dentistry (TPCMD), with passage of the PPACA and the reauthorization of the **Section 747, Primary Care Training and Enhancement**, we urge the Subcommittee to fund the program at \$177.6 million, which is double the amount of funding the program received in FY2005, the high watermark for this program. We urge the Subcommittee to not designate a percentage of the funding to a specific primary care discipline, as has been done in previous years. The reauthorization of the Section 747 program calls for capacity building in the fields of general internal medicine, general pediatrics, and family medicine, as well as eliminates the rateable reduction language which has diverted over two-thirds of the funding in this program to one primary care discipline. The Section 747 program is the only source of federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at

the frontline of patient care, have benefitted from Title VII training models that promoted interdisciplinary training that helped prepare them to work with other health professionals, such as physician assistants, patient educators and psychologists.

The College strongly supports the creation of the **Title VII, Section 749A, Teaching Health Centers Development Grants**, as established in the PPACA, which would provide grants and Graduate Medical Education funding for Teaching Health Centers to train primary care physicians in community based settings. Developing residency programs within community-based ambulatory primary care settings, with the appropriate infrastructure investment, will help strengthen the primary care workforce. Residents in primary care training programs need increased exposure to the ambulatory care setting, a practice environment that demonstrates that satisfaction can be gained from providing ongoing, continuous care to patients. The evidence suggests that residents who spend increased time in outpatient settings opposed to the hospital deliver a higher quality of care and maintained a higher degree of satisfaction from their work. The College strongly urges the Subcommittee to fully fund this program at its FY2011 authorized level of \$50 million.

The College recommends an appropriation of \$414,095,394 million for the **National Health Service Corps** (NHSC), the amount authorized for FY2011 under the PPACA. This is in addition to the \$290 million in enhanced funding the Health and Human Services Secretary has been given the authority to provide to the NHSC through the Community Health Care Fund in FY2011, as authorized under the PPACA. The increase in funds must be sustained to help address the health professionals' workforce shortage and growing maldistribution.

The NHSC scholarship and loan repayment programs provide payment toward tuition/fees or student loans in exchange for service in an underserved area. The programs are available for primary medical, oral, dental, and mental and behavioral professionals. Participation in the NHSC for four years or more greatly increases the likelihood that a physician will continue to work in an underserved area after leaving the program. In 2000, the NHSC conducted a large study of NHSC clinicians who had completed their service obligation up to 15 years before and found that 52 percent of those clinicians continued to serve the underserved in their practice.

At a field strength of 4,760 in FY 2009, the NHSC fell over 24,000 practitioners short of fulfilling the need for primary care, dental, and mental health practitioners in Health Professions Shortage Areas (HPSA), as estimated by HRSA. The NHSC estimates that nearly 50 million Americans currently live in a HPSA and that 27,000 primary care professionals are needed to adequately serve the people living in a HPSA. The National Advisory Council on the NHSC has recommended that Congress double the appropriations for the NHSC to more than double its field strength to 10,000 primary care clinicians in underserved areas. The programs under NHSC have proven to make an impact in meeting the health care needs of the underserved, and with more appropriations, they can do more.

The **Primary Care Extension Program**, a new program created by the PPACA under Title III of the Public Health Service Act, would help to educate and provide technical assistance to primary care providers including general internists currently in practice, about evidence-based therapies, preventive medicine, health promotion, chronic disease management, and mental

health. This much-needed assistance will strengthen primary care practices caring for newly insured individuals and an aging population with multiple chronic conditions. The College encourages the Subcommittee to fund this program at its FY2011 authorized level of \$120 million.

We encourage the Subcommittee to fully fund the necessary amounts for the **National Health Care Workforce Commission**, as created by the passage of the PPACA. The Commission is authorized to review current and projected health care workforce supply and demand and make recommendations to Congress and the Administration regarding national health care workforce priorities, goals, and policies. The College believes the nation needs sound research methodologies embedded in its workforce policy to determine the nation's current and future needs for the appropriate number of physicians by specialty and geographic areas; the work of the Commission is imperative to ensure Congress is creating the best policies for our nation's needs.

The PPACA also establishes a competitive **health care workforce development grant program** for the purpose of enabling state partnerships to complete comprehensive planning and to carry out activities leading to coherent and comprehensive health care workforce development strategies at the state and local levels. We urge the Subcommittee to fully fund the necessary amounts as needed, for both planning and implementation grants, given that our states are an essential link in sustaining our nation's health.

The **Agency for Healthcare Research and Quality** (AHRQ) is the leading public health service agency focused on health care quality. AHRQ's research provides the evidence-based information needed by consumers, providers, health plans, purchasers, and policymakers to make informed health care decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our nation's health and endorses the President's FY2011 budget request of \$611 million. This amount will allow AHRQ to continue its critical health care safety, quality, and efficiency initiatives; strengthen the infrastructure of the research field; reignite innovation and discovery; develop the next generation of scientific pioneers; and ultimately, help transform health and health care.

The College is supportive of AHRQ's investigator-initiated research program, a critically important element of our nation's health care research effort. The funding stream provides for many clinical innovations, innovations that improve patient outcomes, facilitates the translation of research into clinical practice and disease management strategies, and addresses the health care needs of vulnerable populations. Investment in AHRQ's investigator-initiated research is an investment in America's health. Additionally, investment in investigator-initiated research represents a cost-effective and efficient use of our federal health research dollars. The relatively modest investment provided to clinical investigators in the form of grants often result in advancements with positive economic implications far outweighing the original investment.

The PPACA allows the HHS Secretary to establish **State demonstration programs to evaluate alternatives to current medical tort litigation**, such as certificate of merit programs, which require a finding that a suit has merit before it can proceed to trial, and health courts, which would have cases heard by a panel of medical experts rather than a lay jury. ACP believes that reform of medical liability system is essential, and this program is a step in that direction. The

College strongly urges the Subcommittee to fully fund the program at its authorized level of \$50 million immediately, allowing states the opportunity to build upon the work already being done under the October 2009 Funding Opportunity Announcement released by AHRQ, entitled "Medical Liability Reform and Patient Safety Planning Grants."

Conclusion

Mr. Chairman and Ranking Member Tiahrt, I appreciate the opportunity to offer testimony on the importance of the Department of Health and Human Services budget for FY2011.

The College is keenly aware of the fiscal pressures facing the Subcommittee today, but strongly believes the United States must invest in these programs in order to achieve a high performance health care system and build capacity in our public health system. The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress as you begin to work on the FY2011 appropriations process.

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Statement of the
AMERICAN COLLEGE OF PREVENTIVE MEDICINE

submitted to the
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED
AGENCIES SUBCOMMITTEE

COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

for the record on
FISCAL YEAR 2011 APPROPRIATIONS
April 5, 2010

RECOMMENDATION

The American College of Preventive Medicine (ACPM) urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing **\$5 million in FY 2011 for preventive medicine residency training under the public health, dentistry, and preventive medicine line item in Title VII of the Public Health Service Act.** ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition that \$600 million be appropriated in FY 2011 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

THE NEED FOR PREVENTIVE MEDICINE IS GROWING

In today's healthcare environment, the tools and expertise provided by preventive medicine physicians are integral to the effective functioning of our nation's public health system. These tools and skills include the ability to deliver evidence-based clinical preventive services, expertise in population-based health sciences, and knowledge of the social and behavioral aspects of health and disease. These are the tools employed by preventive medicine physicians who practice in public health agencies and in other healthcare settings where improving the health of populations, enhancing access to quality care, and reducing the costs of medical care are paramount. As the body of evidence supporting the effectiveness of clinical and population-based interventions continues to expand, so does the need for specialists trained in preventive medicine.^{1,2,3}

Organizations across the spectrum have recognized the growing demand for public health and preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an "additional 400 residents per year"⁴. The Health Resources and Services Administration's (HRSA) Bureau of Health Professions, using data extracted from the Department of Labor, reports that the demand for public health professionals will grow at twice the rate of all occupations between 2000 and 2010.⁴ The Council on Graduate Medical Education recommends increased funding for training physicians in preventive medicine.⁵ In addition, the nation's medical schools are devoting more time and effort to population health topics.⁶ These are just a few of the examples demonstrating the growing demand for preventive medicine professionals.

In fact, preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties *that requires and provides training in both clinical medicine and public health.* Preventive medicine physicians possess critical knowledge in population and community health issues, disease and injury prevention, disease surveillance and outbreak investigation, and public health research. Preventive medicine physicians are employed in hospitals, state and local health departments, Health Maintenance Organizations (HMOs), community and migrant health centers, industrial sites, occupational health centers, academic centers, private practice, the military, and federal government agencies.

The recent focus on emergency preparedness is also driving the demand for these skills.

Unfortunately, many experts have expressed concerns about the preparedness level of our public health workforce and its ability to respond to emergencies. The non-partisan, not-for-profit Trust for America's Health has published annual reports assessing America's public health emergency response capabilities. The most recent report, released in December 2008, found that neither state nor federal governments are adequately prepared to manage a public health emergency. One reason for this is a significant shortfall in funding needed to improve the nation's public health systems.⁷

Furthermore, the Centers for Disease Control and Prevention recently affirmed that there are significant holes in U.S. hospital emergency planning efforts for bioterrorism and mass casualty management.⁸ These include varying levels of training among hospital staff for treating exposures to chemical, biological or radiological agents; lack of memoranda of understanding with supporting local health care facilities; and lack of preparedness training for explosive incidents. Yet, the skills needed to effectively prepare for and respond to bioterrorism and other public health threats—epidemiologic surveillance, disease prevention and containment, understanding and management of the health systems—are at the heart of preventive medicine training and public health practice. Preventive medicine training produces the public health leaders needed to effectively respond to today's threats to the public's health. A recent article on public health leadership trends showed that health department directors who were not physicians had difficulty handling serious outbreaks and other medical emergencies.⁹

THE SUPPLY OF PREVENTIVE MEDICINE SPECIALISTS IS SHRINKING

According to HRSA and health workforce experts, there are personnel shortages in many public health occupations, including among others, preventive medicine physicians, epidemiologists, biostatisticians, and environmental health workers.¹⁰

Exacerbating these shortages is a shrinking supply of physicians trained in preventive medicine:

- In 2002, *only 6,893* physicians self-designated as specialists in preventive medicine in the U.S., down from 7,734 in 1970. The percentage of total U.S. physicians self-designating as preventive medicine physicians decreased from 2.3% to 0.8% over that time period.¹¹
- Between 1999 and 2006, the number of residents enrolled in preventive medicine training programs declined nearly 20%.¹²
- The number of preventive medicine residency programs decreased from 90 in 1999 to 71 in 2008-2009.¹²

ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. The decline in numbers is dramatic considering the existing critical shortage of physicians trained to carry out core public health activities. This deficiency will lead to major gaps in the expertise needed to deliver clinical prevention and community public health. The impact on the health of those populations served by HRSA may be profound.

FUNDING FOR RESIDENCY TRAINING IS ERODING

Physicians training in the specialty of Preventive Medicine, despite being recognized as an underdeveloped national resource and in shortage for many years, are the only medical residents whose graduate medical education (GME) costs are not supported by Medicare, Medicaid or other third party insurers. Training occurs outside hospital-based settings and therefore is not financed by GME payments to hospitals. Both training programs and residency graduates are rapidly declining at a time of unprecedented national, state, and community need for properly trained physicians in public health and disaster preparedness, prevention-oriented practices, quality improvement and patient safety. Both the Council on Graduate Medical Education and Institute of Medicine have called for enhanced training support.

Currently, residency programs scramble to patch together funding packages for their residents. Limited stipend support has made it difficult for programs to attract and retain high quality applicants; faculty and tuition support has been almost non-existent.¹³ Directors of residency programs note that they receive many inquiries about and applications for training in preventive medicine; however, training slots often are not available for those highly qualified physicians who are not directly sponsored by an outside agency or who do not have specific interests in areas for which limited stipends are available (such as research in cancer prevention).

The Health Resources and Services Administration (HRSA)—as authorized in Title VII of the Public Health Service Act—is a critical funding source for several preventive medicine residency programs, as it represents the largest federal funding source for these programs. HRSA funding (\$2.3 million in 2010) currently supports only ---physicians in --- preventive medicine training programs. An increase of \$2.7 million will allow HRSA to support up to 25 new preventive medicine residents.

These programs directly support the mission of the HRSA health professions programs by facilitating practice in underserved communities and promoting training opportunities for underrepresented minorities:

- **Forty percent** of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate **four times** the average for all health professionals.⁴ These physicians are meeting a critical need in these underserved communities.
- **One-third** of preventive medicine residents funded through HRSA programs are under-represented minorities, which is three times the average of minority representation among all health professionals.⁴ Increased representation of minorities is critical because (1) under-represented minorities tend to practice in medically underserved areas at a higher rate than non-minority physicians, and (2) a higher proportion of minorities contributes to high quality, culturally competent care.
- **Fourteen percent** of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty¹⁶.

**THE BOTTOM LINE: A STRONG, PREPARED, PUBLIC HEALTH SYSTEM
REQUIRES A STRONG PREVENTIVE MEDICINE WORKFORCE**

The growing threats of a flu pandemic, disasters, and terrorism has thrust public health into the forefront of the nation's consciousness. ACPM applauds recent investments in disaster planning, information technology, laboratory capacity, and drug and vaccine stockpiles. However, any efforts to strengthen the public health infrastructure and disaster response capability must include measures to strengthen the existing training programs that help produce public health leaders.

Many of the public health leaders who guided the nation's public health response in the aftermath of the September 11 attacks and the recent hurricane disasters were physicians trained in preventive medicine. According to William L. Roper, MD, MPH, Dean of the School of Public Health, The University of North Carolina at Chapel Hill, "*Investing in public health preparedness and response without supporting public health and preventive medicine training programs is like building a sophisticated fleet of fighter jets without training the pilots to fly them.*"

For more information, contact Paul Bonta, ACPM Associate Executive Director for Policy and Government Affairs, at 202-466-2044, ext. 110 or pbonta@acpm.org

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**WRITTEN TESTIMONY FOR FISCAL YEAR 2011 BUDGET AND APPROPRIATIONS**

Testimony Submitted on Behalf of the American College of Sports Medicine
To the U.S. House of Representatives Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Regarding the U.S. Departments of Health and Human Services and Education
April 16, 2010

On behalf of the American College of Sports Medicine (ACSM), I am pleased to offer this written testimony to the House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for inclusion in the official Committee record. I will focus my comments on the importance of programs within the Department of Health and Human Services (HHS), the Department of Education, and programs recently authorized in the *Patient Protection and Affordable Care Act* (P.L. 111-148) that serve as a means to educate about or provide services that enhance healthy lifestyles for all Americans. Within these programs, ACSM is strongly supportive of the inclusion of provisions that enhance access to information about physical activity and exercise as a mechanism for improving health and reducing chronic diseases or health disparities.

ACSM is a 35,000-member organization that applies knowledge, training, and dedication in sports medicine and exercise science to promote healthier lifestyles for people around the globe. ACSM members are dedicated to improving public health through a spectrum that ranges from basic research to translating that research into effective practice. ACSM members include leading scientists, physicians, educators, public health experts, clinical exercise physiologists, health and fitness professionals, physical therapists, and more.

The nation's focus on physical activity and exercise as a means to improve health and prevent disease has recently been garnering increased attention. However, expanded and sustained federal support is necessary to fully leverage the health benefits that have been shown to result from physical activity and exercise. Additional funding is needed to expand basic and translational research to ensure that the most up-to-date and effective guidance is disseminated and that programs are developed with the goals of keeping Americans strong and healthy and reducing the levels of chronic diseases such as heart disease, diabetes, obesity, stroke, osteoporosis, and depression.

In particular, scientific and medical research conducted at the National Institutes of Health (NIH) will be instrumental in building on current efforts to improve the nation's health and reduce diseases and health disparities. ACSM appreciates the Committee's past support for NIH and

encourages the Committee to maintain its commitment by allocating a total discretionary budget of \$32.239 billion, which is equal to the President's FY 2011 budget request for NIH. ACSM also encourages the Committee to direct a portion of this increased funding toward institutes and programs that focus on prevention and wellness. The combination would allow NIH to fund a record number of research grants, including those that will help us to understand what is needed to ensure Americans live healthier lifestyles.

In addition, summarized below are recommendations for FY 2011 funding for programs within HHS, the Department of Education, and new programs recently authorized through the *Patient Protection and Affordable Care Act* (P.L. 111-148) to help ensure that the necessary mechanisms are provided to improve health, eliminate disparities, and reduce diseases among all Americans.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

The agencies within HHS include programs that support ACSM's goals. ACSM urges the Committee's support for the following HHS programs:

Community Health Centers – ACSM appreciates the Committee's support for the Health Centers program within the Health Resources and Services Administration (HRSA). The Health Centers program provides access to comprehensive primary health care, including supportive services such as transportation and education for individuals and families in high-need communities. ACSM urges the Committee to appropriate at least the President's FY 2011 request of \$2.5 billion for the program, an increase of \$290 million above the FY 2010 enacted level and to direct a portion of this funding to allow new and existing centers to expand to include services and information that highlight the health benefits of physical activity and exercise.

Centers for Disease Control and Prevention – ACSM supports the increases proposed in the President's FY 2011 budget request for programs within the Centers for Disease Control and Prevention (CDC), including: Chronic Disease Prevention, Health Promotion and Genomics, a total of \$937 million; Public Health Research, a total of \$31 million; and Preventive Health and Health Services Block Grant, a total of \$102 million. ACSM urges the Committee to direct a portion of the funding within these programs to physical activity and exercise programs and research.

PATIENT PROTECTION AND AFFORDABLE CARE ACT

ACSM urges the Committee to fund the following programs authorized in the *Patient Protection and Affordable Care Act* (P.L. 111-148), which deal with prevention of chronic disease and improving public health:

Prevention and Public Health Fund – This fund would be administered by the Secretary of HHS and would increase funding for programs authorized by the Public Health Service Act for prevention, wellness, and public health activities. ACSM urges the Committee to use its authority to transfer money from the fund to existing or new programs authorized by the Public Health Service Act that have a particular focus on physical activity and exercise, including the Community Transformation grant program.

U.S. Preventive Services Task Force/Community Preventive Services Task Force – These task forces will coordinate with the Advisory Committee on Immunization Practices, and will comprise experts to review scientific evidence related to effectiveness, appropriateness, and cost-effectiveness of clinical preventive services for the purpose of developing recommendations to be widely distributed to and utilized by the public. ACSM urges the Committee to appropriate the necessary funding to establish these task forces, in order to help ensure that the best practices in health and wellness, including physical activity and exercise guidelines and recommendations, are being promoted.

Education and Outreach Campaign – This campaign would be developed by a public-private partnership with the aim of raising public awareness of health improvement across the life span. ACSM urges the Committee to appropriate funding to allow for successful development and implementation of the campaign.

DEPARTMENT OF EDUCATION

ACSM urges the Committee to support the following program at the Department of Education:

Carol M. White Physical Education Program/Successful, Safe, and Healthy Students – ACSM supports programming within the Department of Education that focuses on developing healthy lifestyles for students and the nation's youth population. In the President's FY 2011 budget request, the Carol M. White Physical Education Program was proposed for consolidation into an overarching Successful, Safe, and Healthy Students program, of which one goal is improving students' physical health and well-being through the use of, or access to, comprehensive services that improve student physical activity and fitness. ACSM urges the Committee to provide increased funding for the Carole M. White Physical Education Program or direct a significant portion of the funding provided to the Successful, Safe, and Healthy Students program to focus on physical activity, exercise, and the development of healthy lifestyles for youth.

I appreciated the opportunity to submit these recommendations and hope the Committee will consider them while developing appropriations for FY 2011.

Sincerely,



James R. Whitehead
Executive Vice President

Testimony Submitted by the
American Congress of Obstetricians and Gynecologists (ACOG)

US House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
Department of Health and Human Services (HHS)

Contact Person: Anna Hyde, Government Affairs Staff, ahydc@acog.org, 202-863-2512

The American Congress of Obstetricians and Gynecologists, representing 53,000 physicians and partners in women's health care, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Obey, and the entire Subcommittee for their leadership to continually address women's health research at the Department of Health and Human Services. Today, the US lags behind other nations in healthy births, yet remains high in birth costs. ACOG's Making Obstetrics and Maternity Safer (MOMS) Initiative seeks to improve maternal outcomes through more research and better data, and we urge you to make this a top priority in FY11.

Research is critically needed to understand why our maternal and infant mortality rate remains comparatively high. Having better data collection methods and comprehensive maternal mortality reviews has shown maternal mortality rates in some states, such as California, to be higher than previously thought. States without these resources are likely underreporting maternal and infant deaths and complications from childbirth. Without accurate data, the full range of causes of these deaths remains unknown. Effective research based on comprehensive data is a key MOMS element to developing and implementing evidence-based interventions.

Unfortunately, the MOMS Initiative is threatened by the sizeable cliff in research funding that will be created in FY11 once the stimulus package ends this year. Building funding levels from the stimulus into the base for FY11 appropriations will ensure the continuation of current research important to the MOMS Initiative, and ensure that future research necessary to improving maternal outcomes does not go un-funded.

The President's budget for FY11 takes a positive first step towards this goal, including a \$1 billion increase for NIH, and ACOG requests the Subcommittee build on these increases to maintain the momentum created by the stimulus. The NIH and many other HHS agencies are vital to carrying out the goals of the MOMS Initiative. Therefore, ACOG asks for a 13.5% increase for NIH to \$35.2 billion, a 22.3% increase for HRSA to \$9.15 billion, a 35.9% increase for CDC to \$8.8 billion, and a 53.9% increase for AHRQ to \$611 million.

Research and programs in the following areas are vital to the MOMS Initiative:

Maternal/Child Health Research at the NIH

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) conducts the majority of women's health research. Despite the NIH's critical advancements, reduced funding levels have made it difficult for research to continue.

ACOG supports a 12.5% increase in funds over FY10 to \$1.495 billion for the NICHD. These funds will assist the following research areas critical to the MOMS Initiative:

Reducing the Prevalence of Premature Births

There is a known link between pre-term birth and infant mortality, and women of color are at increased risk for delivering pre-term. NICHD is helping our Nation understand how adverse conditions and health disparities increase the risks of premature birth in high-risk racial groups, and how to reduce these risks. Prematurity rates have increased almost 35% since 1981, accounting for 12.5% of all births, yet the causes are unknown in 25% of cases. Preterm births cost the nation \$26 billion annually, \$51,600 for every infant born prematurely. Direct health care costs to employers for a premature baby average \$41,610, 15 times higher than the \$2,830 for a healthy, full-term delivery.

ACOG supports the Surgeon General's effort to make the prevention of pre-term birth a national public health priority, and urges Congress to allocate \$1 million to NICHD to create a Trans-disciplinary Research Center on Prematurity to help streamline efforts to reduce pre-term births.

Obesity Research, Treatment and Prevention

Obese pregnant women are at higher risk for poor maternal and neonatal outcomes. Additional research and interventions are needed to address the increased risk for poor outcomes in obese women receiving infertility treatment, the increased incidence of birth defects and stillbirths in obese pregnant women, ways to optimize outcomes in obese women who become pregnant after bariatric surgery, and the increased future risk of childhood obesity in their offspring.

ACOG is grateful to the NIH for making obesity a priority and initiating trans-disciplinary approaches to combat obesity. We also applaud First Lady Michelle Obama for naming childhood obesity a top priority. ACOG urges the NIH and the NICHD to make obesity in pregnant women a high priority, to improve the health of mother and child.

Maternal/Child Health Programs at CDC:

CDC funds programs that are critical to providing resources to mothers and children in need. Where NIH conducts research to identify causes of pre-term birth, CDC funds programs that provide resources to mothers to help prevent pre-term birth, and help identify factors contributing to pre-term birth and poor maternal outcomes.

ACOG supports a 35.9% increase in funds over FY10 to \$8.8 billion to increase CDC's ability to bring prevention, treatment and interventions to more women and children in need, and to help enact some of the important provisions within health care reform. This funding will help the following programs important to the MOMS Initiative:

Maternal Mortality Reviews, Division of Reproductive Health

National data on maternal mortality is inconsistent and incomplete due to the lack of standardized reporting definitions and mechanisms. To capture the accurate number of maternal deaths and plan effective interventions, maternal mortality should be addressed through multiple, complementary strategies. ACOG recommends that CDC fund states in implementing maternal mortality reviews that would allow them to conduct regular reviews of all deaths within the

state to identify causes, factors in the communities, and strategies to address the issues. Combined with adoption of the recommended birth and death certificates in all states and territories, CDC could then collect uniform data to calculate an accurate national maternal mortality rate. Results of maternal mortality reviews will inform research needed to identify evidence based interventions addressing causes and factors of maternal mortality and morbidity.

ACOG urges Congress to provide \$2.375 million to the Division of Reproductive Health to assist states in setting up maternal mortality reviews.

Electronic Birth Records and Death Records, National Center for Health Statistics (NCHS), National Vital Statistics System (NVSS)

NCHS is the nation's principal health statistics agency; it collects, analyzes and reports on data critical to all aspects of our health care system. NCHS collects state data needed to monitor maternal and infant health, such as use of prenatal care, and smoking during pregnancy. This data allows investigators to monitor maternal and child health objectives, and develop efficient prevention and treatment strategies.

Uniform consistent data from birth and death records is critical to conducting research and directing public programs to combat maternal and infant death. Only 75 percent of states and territories use the 2003-recommended birth certificates and 65 percent have adopted the 2003-recommended death certificate. Within the increased funding provided to NCHS in the President's budget, \$8 million was included specifically for the National Vital Statistics System (NVSS) to support states and territories in implementing the 2003 birth certificate and modernizing their infrastructure to collect these data electronically to expand the scope and quality of data collected on a national basis. The President's budget provides NVSS \$3 million to phase in the 2003 death certificate and electronic death records in states and territories.

ACOG urges Congress to allocate \$11 million for states to modernize their birth and death records systems to the 2003-recommended guidelines, consistent with the President's budget.

Safe Motherhood/Infant Health

2-3 women a day die from delivery complications. The Safe Motherhood Program supports CDC's work with state health departments and other groups to identify and gather information on pregnancy-related deaths; collect and provide information about women's health and health behaviors before, during, and immediately after pregnancy; and expand the acceptance and use of findings and guidelines on preconception care into everyday practice and health care policy.

Safe Motherhood also tracks infant morbidity and mortality associated with pre-term birth. ACOG is concerned with recent trends particularly among rates of late pre-term births. Increased funding is needed for CDC to improve national data systems to track pre-term birth rates and expand epidemiological research that focuses especially on the causes and prevention of preterm birth and births at 37-38 weeks gestation.

ACOG urges Congress to include a 23.7% increase in funds to \$55.4 million for Safe Motherhood, consistent with the President's budget.

Maternal/Child Health Programs at HRSA

HRSA delivers critical resources to communities to improve the health of mothers and children. ACOG urges a 22.3% increase in funds over FY10 to \$611 million to increase the scope of HRSA programs, ultimately bringing more resources to more mothers and children. This funding will help expand the following programs important to the MOMS Initiative:

Fetal Infant Mortality Reviews, Healthy Start Program

After decades of decline, the U.S. infant mortality rate is again on the rise and is particularly severe among minority and low-income women. The infant mortality rate among African American women has been increasing since 2001 and reached 14.2 deaths per 1,000 births in 2004. There also has been a startling rise in infant mortality in the South. Mississippi, for example, had an infant mortality rate of 11.4 in 2005 compared to 9.6 the previous year.

The Healthy Start Program through HRSA promotes community-based programs that focus on infant mortality and racial disparities in perinatal outcomes. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to help solve problems related to infant mortality. Today more than 220 local programs in 42 states find FIMR a powerful tool to help solve infant mortality.

ACOG urges Congress to include \$.5 million for Healthy Start Programs to include FIMR.

Maternal Child Health Block Grant (MCH)

The MCH is the only federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block Grant funds to reduce infant mortality, deliver services to children and youth with special health care needs, support comprehensive prenatal and postnatal care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

ACOG urges Congress to increase funding for MCH \$730 million, a 10.3% increase over FY10.

Comparative Effectiveness Research on Maternal Disparities at AHRQ

There are glaring disparities in maternal outcomes among different ethnic and racial groups, particularly related to pre-term birth and maternal and infant mortality rates among African American women. For that reason, disparities research is a major tenant of ACOG's MOMS Initiative. Comparative effectiveness research has the capacity to greatly improve pre-term birth rates and maternal and infant mortality rates by testing the efficacy of prevention and treatment interventions on different populations. As more comparative effectiveness research gets funded from the stimulus and health care reform bills, ACOG urges Congress to make disparities research into maternal outcomes a top priority.

ACOG supports a 53.9% increase in funds for AHRQ to \$611 million, consistent with the President's budget.

Again, we would like to thank the Committee for its continued support of programs to improve women's health, and we urge you to consider our MOMS Initiative in FY11.



AMERICAN COUNSELING ASSOCIATION

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Written Testimony for the FY 2011 Public Witness Record

**House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
2358-C Rayburn House Office Building**

Submitted Electronically
to lh.approp@mail.house.gov
on April 14, 2010

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April 14, 2010

The Honorable David R. Obey, Chairman
The Honorable Todd Tiart, Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
House Committee on Appropriations
Washington, DC 20515

Dear Chairman Obey and Ranking Member Tiart:

On behalf of the American Counseling Association (ACA), the nation's largest non-profit organization representing school counselors and professional counselors working in other settings, we respectfully request that you provide \$80 million in funding for the Elementary and Secondary School Counseling Program (ESSCP) for fiscal year (FY) 2011. ESSCP is the only federal program that provides funds specifically for developing and expanding comprehensive school counseling programs.

As you know, the president's FY 2011 budget request calls for the elimination of this important program. Though ACA appreciates the administration's interest in improving school climate, eliminating ESSCP will substantially reduce students' access to professional school counselors, school social workers and school psychologists, and the comprehensive school counseling programs and services they provide. This is especially concerning in light of recent studies showing students' mental health and social/emotional needs continue to rise.

Congress has strongly supported ESSCP over the years, ensuring that this important program has received a continued increase in funding. In FY 2008, Congress provided \$48.6 million for the program, exceeding the \$40 million statutory funding trigger; thus, in addition to elementary schools, middle and high schools were also eligible to apply for ESSCP grants for the first time. ESSCP increased to \$55 million for FY 2010. However, because of the trigger, only \$15 million of ESSCP's FY 2010 funds can go to middle and high schools. Thus, funding ESSCP at \$80 million for FY 2011 would ensure equal funding for both elementary and secondary schools.

Given the extraordinarily high student-to-professional ratios in many schools, more school counselors, school social workers and school psychologists are needed in order to meet the great demand and to fully realize the benefits of comprehensive school counseling programs. Currently, the average student-to-counselor ratio across the country is 467 to 1, nearly double ACA's recommended ratio of 250 to 1. The related professions also experience caseloads well above their recommended ratios. The School Social Work Association of America recommends a student-to-school social worker ratio of 400 to 1, and the National Association of School Psychologists recommends a student-to-school psychologist ratio of 500-700 to 1 when school psychologists are providing comprehensive services.

The need for increased funding of ESSCP is also illustrated by the huge demand for federal assistance to build the capacity for school counseling programs in school districts across the country. The current funding level allows support for only 1 in 10 applications. In 2009, 64

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school districts – comprising more than 850 schools and more than 429,000 students – across 29 states obtained new grants to establish or expand school counseling programs and services. The administration's FY 2011 budget proposal to eliminate ESSCP would threaten the capacity-building efforts of existing grantees and eliminate the absolute priorities that seek to meet this growing public demand for school counseling programs.

Highly trained and licensed/certified to work in school settings, professional school counselors, school social workers and school psychologists provide *the full range of students*, across general- and special-education, with essential "9 a.m. to 3 p.m." mental health services and academic supports. This is the most cost-effective way to address current student problems that impose barriers to learning, while also identifying problems early on, preventing future problems, and helping students and schools achieve college and career readiness. These professionals also provide expert consultation to and collaboration and coordination with teachers, principals, families and community-based professionals who provide the "3 p.m. to 9 p.m." services for students and families requiring more intensive or extended care.

Moreover, comprehensive school counseling programs have been found to positively impact numerous school factors, including academic achievement, school safety, and post-secondary outcomes. Consider the following:

- A recent meta-analysis of school counseling outcome research involving 117 studies of 153 school counseling interventions with 16,296 students found a significant effect size of .30. This means that the students who participated in the school counseling interventions improved almost a third of a standard deviation more than their peers who did not receive the interventions.¹
- Surveying 22,601 students, and after researchers controlled for socioeconomic status and enrollment size, students attending middle schools with more fully implemented comprehensive counseling programs reported earning higher grades, having fewer problems related to the physical and interpersonal milieu in their schools, feeling safer attending their schools, having better relationships with their teachers, believing that their education was more relevant and important to their futures, and being more satisfied with the quality of education available to them in their schools.²
- A state-wide study of Missouri high schools found that students in schools with more fully implemented school counseling programs were more likely to report that they had earned higher grades, their education was better preparing them for the future, their school made more career and college information available to them, and their school had a more positive climate (greater feelings of belonging and safety at school, classes less likely to be interrupted, peers behaving better). After controlling for school enrollment size and socioeconomic status, positive program effects were still found.³

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As other recent studies have documented, high quality school counseling services enable teachers and principals to move beyond antiquated systems to real reforms, improving student behavior, well-being and achievement. School-employed mental health professionals are also instrumental in implementing school climate initiatives and in managing partnerships with community providers to make community schools successful. Thus, to achieve desired goals, even the best teachers and principals need a strong complement of professional school counselors, school social workers and school psychologists spearheading a comprehensive school counseling program.

With education budgets reeling and families experiencing enormous hardships in the wake of the recession, now is the time to increase, not eliminate, federal support for the Elementary and Secondary School Counseling Program. Thank you for this opportunity to submit written testimony on this important matter. If you have questions, please contact Dominic W. Holt, MSW, MFA in the ACA Office of Public Policy and Legislation at (703) 823-9800, ext. 242, or dholt@counseling.org.

Sincerely,



Lynn E. Linde, Ed.D.
President
American Counseling Association

¹ Whiston, S. C. & Quinby, R. F. (2009). Review of school counseling outcome research. *Psychology in the Schools*, 46(3), 267-272.

² Lapan, R.T., Gysbers, N.C., & Petroski, G.F. (2001). Helping seventh graders be safe and successful: A statewide study of the impact of comprehensive guidance and counseling programs. *Journal of Counseling and Development*, 79, 320-330.

³ Lapan, R.T., Gysbers, N.C., & Sun, Y. (1997). The impact of more fully implemented guidance programs on the school experiences of high school students: A statewide evaluation study. *Journal of Counseling & Development*, 75, 292-302.



**Statement of the
American Dental Education Association (ADEA)
Fiscal Year 2011 Appropriations
House Appropriations Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies**

April 16, 2010

The American Dental Education Association (ADEA) is pleased to offer its recommendations for FY 2011 appropriations for dental education and research.

The American Dental Education Association represents all 60 dental schools in the United States, in addition to more than 700 dental residency training programs and nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. It is at these academic dental institutions that future practitioners and researchers gain their knowledge, where the majority of dental research is conducted, and where significant dental care is provided. ADEA member institutions serve as dental homes for a broad array of racially and ethnically diverse patients, many who are uninsured, underinsured, or reliant on public programs such as Medicaid and the Children's Health Insurance Program for their health care.

ADEA's requests build upon funding from the American Economic Recovery and Reinvestment Act (ARRA) and the Labor, Health and Human Services and Education fiscal year 2010 Appropriations. The Department of Health and Human Services has several oral health programs that address the various aspects needed to improve oral health care in America. These programs build and sustain State oral health departments, fund proven public health programs to prevent oral disease, target research to eradicate dental disease, and work to develop an adequate workforce of dentists with advanced training to serve children, the aged and those suffering from specific diseases like AIDS.

Our budget recommendations include the following:

- I. **Dental Education:** The Title VII Health Professions Education and Training Programs and Diversity and Student Aid Programs, administered by the Health Resources and Services Administration (HRSA);
- II. **Oral Health Research:** The National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR); and

The mission of the American Dental Education Association is to help individual and institutions of the dental education community to address contemporary issues in dentistry, practice, research, and the delivery of oral health care for the improvement of the health of the public.

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- III. Access to Care: The Ryan White CARE Act HIV/AIDS Dental Reimbursement Program and the Community-Based Dental Partnerships Program; the Dental Health Improvement Act; the Oral Health Program at the Centers for Disease Control and Prevention (CDC); and the National Health Service Corps (NHSC).

Specifically, the American Dental Education Association respectfully urges the Subcommittee to provide \$30 million for Sec. 5303 of (P.L. 111-148) for the continuation and enhancement of dental training programs. The following programs help to address the nation's oral health care needs:

I. Dental Education

- **\$16 million for General Dentistry and Pediatric Dentistry Residency Training in the Title VII Health Professions Programs**

The Title VII General and Pediatric Dentistry Programs are critical to building the primary care dental workforce. Support for these programs is essential to expanding existing or establishing new general dentistry and pediatric dentistry residency programs, which have shown to be effective in increasing access to dental care for vulnerable populations, including patients with developmental disabilities, children, and geriatric patients. These primary care dental residency programs generally include outpatient and inpatient care and afford residents an excellent opportunity to learn and practice in all phases of primary care dentistry, including trauma and emergency care, and comprehensive ambulatory dental care for adults and children.

- **\$118 million for Diversity and Student Aid**
 - **33 million for Centers of Excellence (COE)**
 - **49 million for Scholarships for Disadvantaged Students (SDS)**
 - **35 million for Health Careers Opportunity Program (HCOP)**
 - **1.3 million for Faculty Loan Repayment Program (FLRP)**

The Title VII Diversity and Student Aid programs play a critical role in helping to diversify the health profession's student body and thereby the health care workforce. Blacks, Hispanics, and American Indians currently represent more than 25 percent of the U.S. population. By the year 2050, nearly one in five Americans (19 percent) will be an immigrant, compared with one in eight (12 percent) in 2005. Despite these population trends, minorities are underrepresented in the U.S. health care workforce. This is no less true of dentistry, where they comprise less than five percent of dentists and about nine percent of dental faculty. For the last several years, these programs have not enjoyed an adequate level of funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population.

II. Oral Health Research

- **\$35 billion for the National Institutes of Health, including \$463 million for the National Institute of Dental and Craniofacial Research (NIDCR)**

Discoveries stemming from dental research have reduced the burden of oral diseases, led to better oral health for tens of millions of Americans, and uncovered important associations between oral and systemic health. Dental researchers are poised to make new breakthroughs that can result in dramatic progress in medicine and health, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease

from saliva instead of blood samples; and deciphering the complex interactions and causes of oral health disparities involving social, economic, cultural, environmental, racial, ethnic, and biological factors. Dental research is the underpinning of the profession of dentistry. With grants from NIDCR, dental researchers in academic dental institutions have built a base of scientific and clinical knowledge that has been used to enhance the quality of the nation's oral health and overall health.

Dental scientists also are putting science to work for the benefit of the health care system through translational research, comparative effectiveness research, health information technology, health research economics, and further research on health disparities. NIDCR continues to make disparities a priority by renewing five disparities centers for 2008 – 2015: Boston University Henry M. Goldman School of Dental Medicine, the University of California San Francisco School of Dentistry, the University of Colorado Denver School of Dental Medicine, the University of Florida College of Dentistry, and the University of Washington School of Dentistry.

The latest NHANES data that provided a full dental examination, 1999-2004, show that dental caries in young children has actually increased, particularly in those populations covered by SCHIP and Medicaid. The June 2009 IOM Study on Comparative Effectiveness Research (CER) included two oral health topics in the top 100 national priorities for CER.

NIDCR funded 4 ARRA Challenge Grants on CER. Investments in dental research will produce inventions that make corporations more competitive in the global economy and benefit everyone with new businesses and jobs. Investments in dental research will produce inventions that make corporations more competitive in the global economy and benefit everyone with new businesses and jobs. It is important to note that NIH disproportionately creates higher-paying employment opportunities that require a higher level of technical sophistication in construction, staffing, and supporting laboratories. The average wage associated with jobs created through NIH grants and contracts was \$52,000 in 2007.

III. Access to Dental Care

- **\$19 million for the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program, Part F of the Ryan White HIV/AIDS Treatment and Modernization Act**

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. By providing reimbursement to dental schools and schools of dental hygiene, the Dental Reimbursement Program provides access to quality dental care for people living with HIV/AIDS while simultaneously providing educational and training opportunities to dental residents, dental students, and dental hygiene students who deliver the care. The Dental Reimbursement Program is a cost-effective federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Particularly important to this program is the fact that Congress designated dental care as a "core medical service" when it reauthorized the Ryan White program in 2006.

The Community-Based Dental Partnership Program fosters partnerships between dental schools and communities lacking academic dental institutions to ensure access to dental care for HIV/AIDS patients living in those areas.

- **\$20 million for the Dental Health Improvement Act (DHIA)**

This program supports the development of innovative dental workforce programs specific to states' dental workforce needs and increases access to dental care for underserved populations. In FY 2006, Congress provided first-time DHIA funding of \$2 million to assist states in developing innovative dental workforce programs. The inaugural grant cycle, held in FY 2006, yielded 36 applications from states. Eighteen states were awarded grants ranging from \$67,865 to \$124,080. Grants are being used to support a variety of initiatives including, but not limited to, loan repayment programs to recruit culturally and linguistically competent dentists to work in underserved areas with underserved populations including the developmentally disabled; rotating residents and students in rural areas; recruiting dental school faculty; training pediatricians and family medicine physicians to provide oral health services (screening exams, risk assessments, fluoride varnish application, parental counseling, and referral of high-risk patients to dentists); and supporting teledentistry.

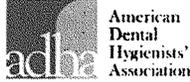
- **\$33 million for the Oral Health Programs at the Centers for Disease Control and Prevention (CDC)**

The CDC Oral Health Program expands the coverage of effective prevention programs. The program increases the basic capacity of state oral health programs to accurately assess the needs of the state, organize and evaluate prevention programs, develop coalitions, address oral health in state health plans, and effectively allocate resources to the programs. CDC's funding and technical assistance to states is essential to help oral health programs build capacity. Increasing the funding will help to ensure that all states that apply may be awarded an oral health grant.

- **\$414 million for the National Health Service Corps (NHSC)**

The NHSC scholarship and loan repayment program provides awards to health care professionals, including dentists and dental hygienists who agree to work in underserved communities for a minimum of two years. Participants must work in a Health Professional Shortage Area (HPSA), and dentists and dental hygienists work in Dental Health Professional Shortage Areas (Dental HPSAs). According to the Health Resources and Services Administration (HRSA) there are 4,230 Dental HPSAs with 49 million people living in them. It would take 9,642 practitioners to meet their need for dental providers (a population to practitioner ratio of 3,000:1). The dedicated clinicians of the NHSC provide quality care to millions of people who would otherwise lack adequate access to health services.

The American Dental Education Association is grateful to the Committee for considering our FY 2011 budget requests for federal agencies and programs that sustain and enhance dental education, oral health research, and access to care. A continuing federal commitment is needed to help meet the challenges oral diseases pose to the nation's most vulnerable citizens, including children. Also critical is the development of a partnership between the federal government and dental education programs to implement a national oral health plan that guarantees access to dental care for everyone, ensures continued dental health research, and eliminates disparities and workforce shortages.



**Written Testimony of Lynn Ramer, LDH
President, American Dental Hygienists' Association**

Submitted to the
United States House of Representatives
Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Honorable David Obey, Chair

On FY 2011 Appropriations for the Department of Health and Human Services Impacting Oral Health

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On behalf of the American Dental Hygienists' Association (ADHA), thank you for the opportunity to submit testimony regarding appropriations for Fiscal Year (FY) 2011. ADHA appreciates the Subcommittee's past support of programs that seek to improve the oral health of Americans and to bolster the oral health workforce. Oral health is a part of total health and authorized oral health care programs require appropriations support in order to increase the accessibility of oral health services, particularly for the underserved.

ADHA is the largest national organization representing the professional interests of more than 152,000 licensed dental hygienists across the country. Dental hygienists are primary care providers of oral health services and are licensed in each of the fifty states. Hygienists are committed to improving the nation's oral health, a fundamental part of overall health and general well-being. In order to become licensed as a dental hygienist, an individual must graduate from an accredited dental hygiene education program and successfully complete a national written and a state or regional clinical examination.

This Congress has clearly demonstrated – through the inclusion of a pediatric oral health benefit in the essential benefits package and the inclusion of significant other oral health workforce and prevention/infrastructure provisions in the Patient Protection and Affordable Care Act (PPACA) signed into law less than a month ago (P.L. 111-148) and through inclusion of a guaranteed dental benefit in the Children's Health Insurance Program Reauthorization Act

passed last year – that oral health is essential to overall health and general well-being. ADHA applauds inclusion of these oral health provisions in health reform legislation.

However, the workforce and prevention provisions will be mere words on a page if they are not funded. And the promise of a dental benefit will similarly be unfulfilled if the supply of oral health providers is insufficient to ensure access to services. Indeed, with a pediatric dental benefit in the essential benefit package and an estimated additional 16 million people gaining Medicaid coverage, the already severe oral health access crisis will only be exacerbated if this Subcommittee does not ensure that oral health workforce and other programs at the Health Resources and Services Administration (HRSA) – the “access agency” – are not fully funded this year and into the future. ADHA is pleased to join with the Friends of HRSA in supporting overall funding of at least \$9.3 billion for HRSA for FY 2011

In order to realize the promise of the oral health provisions in the PPACA and to allow an increasing number of Americans to maximize their oral health and to benefit from the proven prevention capacity in oral health, ADHA urges full funding of all authorized oral health programs and describes some of the key oral health programs below:

**Title VII Program Grants to Expand and Educate the Dental Workforce –
Fund at a level of \$30 million in FY 2011**

A number of existing grant programs offered under Title VII support health professions education programs, students, and faculty. ADHA is pleased that Congress in the PPACA recognized that dental hygienists are primary care providers of oral health services and included dental hygiene in a reconfigured primary care dental training program. Section 5303 of the PPACA (Section 748 of the Public Health Service Act) is entitled “Training in General, Pediatric, and Public Health Dentistry” supports the expansion and development of the oral health workforce with an emphasis on providers and programs.

With millions more Americans eligible for dental coverage in coming years, it is critical that the oral health workforce is bolstered. Dental and dental hygiene education programs currently struggle with significant shortages in faculty and there is a dearth of providers pursuing careers in public health dentistry and pediatric dentistry. Securing appropriations to expand the Title VII grant offerings to additional dental hygienists and dentists will provide much needed support to programs, faculty, and students in the future.

ADHA recommends funding at a level of \$30 million for FY 2011.

**Alternative Dental Health Care Provider Demonstration Project Grants –
Fund at a level of \$30 million in FY 2011**

P.L. 111-148 establishes a new grant program (Section 5304 of the PPACA) to provide demonstration grants to up to 15 programs that train or employ alternative dental health providers. States have increasingly been pioneering new dental delivery models to extend access to oral health care services to those currently unable to access needed care. The grants

contained in Section 5304 support state-level efforts to better utilize the existing oral health workforce as well as develop new provider models.

A number of dental hygiene-based models are listed as eligible for the grants, including advanced practice hygienists, public health hygienists, and independent dental hygienists. Grants under Section 5304 could also be awarded to dental therapist models, programs where physicians/other medical providers deliver basic dental services, and other models deemed appropriate by the Secretary of Health and Human Services.

Currently, more than 30 states have statutes and rules that allow dental hygienists to work in community-based settings (like public health clinics, schools, and nursing homes) to provide oral health services without the presence or direct supervision of a dentist. These models extend the reach of dental professionals beyond the private dental office. ADHA has developed a proposal for a new dental provider, the Advanced Dental Hygiene Practitioner (ADHP), a Master's level educated provider envisioned to serve as the oral health equivalent of the nurse practitioner in medicine. Currently, Connecticut has legislation pending to establish an ADHP pilot program in the state.

In 2009, Minnesota became the first state in the country to pass legislation to authorize the practice of two new providers – the dental therapist and advanced dental therapist. An education program based on the ADHP Competencies that is designed to facilitate the training of advanced dental therapist students began at Metropolitan State University in September 2009. The new providers will begin to enter the workforce in 2011.

Additionally, at least four state dental associations are currently developing their own dental therapist provider models. Given the great need for innovation in the dental delivery system, these grants are an important way in which the federal government can support the efforts of states to extend care to those who currently have no or limited access to care.

The American Dental Education Association supports funding of this program. The PEW Charitable Trusts Children's Dental Campaign also supports funding of this program.

ADHA recommends funding at a level of \$30 million for FY 2011 to support these vital demonstration projects. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated.

**Oral Health Prevention and Education Campaign –
Fund at a level of \$2 million in FY 2011**

A targeted national campaign led by the Centers for Disease Control to educate the public, particularly those who are underserved, about the benefits of oral health prevention could vastly improve oral health literacy in the country. While significant data has emerged over the past decade drawing the link between oral health and systemic diseases like diabetes, heart disease, and stroke, many remain unaware that neglected oral health can have serious ramifications to their overall health. Data is also emerging to highlight the role the impact that

poor oral health in pregnant women has on their children, including a link between periodontal disease and low-birth weight babies.

ADHA strongly supports funds for Section 4102(a) in P.L. 111-148 for a national oral health prevention and education campaign. Dental hygienists take a lead role in the administration of preventive oral health services and in patient oral hygiene education and could be engaged to assist in developing and carrying out a national campaign.

ADHA advocates an allocation of \$2 million in FY 2011 for a national oral health prevention and education campaign.

School-Based Sealant Programs –

Fund at a level sufficient to ensure school-based sealant programs in all 50 states

Sealants have long-proven to be low-cost and effective in preventing dental caries (cavities), particularly in children. While most dental disease is fully preventable, dental caries remains the most common childhood disease, five times more common than asthma, and more than half of all children age 5-9 have a cavity or filling. Section 4102(a) of P.L. 111-148 would expand school-based sealant programs to include all 50 states and territories.

The death of twelve-year old Deamonte Driver in 2007 from complications of an abscessed tooth provided all of us with a tragic reminder that lack of access to oral health services can have serious – even fatal – consequences. Deamonte’s death from a dental infection is particularly heartbreaking because virtually all dental disease is fully preventable. Timely sealant placement on this school-age boy would likely have prevented his tragic death.

The CDC has noted that data collected in evaluations of school-based sealant programs indicates the programs are effective in stopping and preventing dental decay. Significant progress has been made in developing best practices for school-based sealant programs, yet most states lack well developed programs as a result of funding shortfalls. ADHA encourages the transfer of funding from the Public Health and Prevention Fund sufficient to allow CDC to meaningfully fund school-based sealant programs in all 50 states in FY 2011

Centers for Disease Control Division of Oral Health –

Fund at a level of \$33 million in FY 2011

ADHA joins with others in the dental community in urging \$33 million for the Centers for Disease Control Oral Health Division of Oral Health. This funding level will enable CDC to continue its vital work to control and prevent oral disease, including vital work in community water fluoridation. Federal grants to facilitate improved oral health leadership at the state level, support the collection and synthesis of data regarding oral health coverage and access, and promote the integrated delivery of oral health and other medical services are directed by Section 4102(a) of P.L. 111-148. Grants of that nature enable states to innovate new types of oral health programs and promote a data-driven approach to oral health programming.

ADHA advocates for \$33 million in funding for grants to improve and support oral health infrastructure and surveillance.

**Dental Health Improvement Grants –
*Fund at a level of \$20 million in FY 2011***

HRSA administered dental health improvement grants are an important resource for states to have available to develop and carry out state oral health plans and related programs. Past grantees have used funds to better utilize the existing oral health workforce to achieve greater access to care. Previously awarded grants have funded efforts to increase diversity among oral health providers in Wisconsin, promote better utilization of existing workforce including the extended care permit (ECP) dental hygienist in Kansas, and in Virginia implement a legislatively directed pilot program to allow patients to directly access dental hygiene services.

ADHA supports funding of HRSA dental health improvement grants at a level of \$20 million for FY 2011.

**National Institute of Dental and Craniofacial Research –
*Fund at a level of \$463 million in FY 2011***

The National Institute of Dental and Craniofacial Research (NIDCR) cultivates oral health research that has led to a greater understanding of oral diseases and their treatments and the link between oral health and overall health. Research breeds innovation and efficiency, both of which are vital to improving access to oral health care services and improved oral status of Americans in the future.

ADHA joins with others in the oral health community to support NIDCR funding at a level of \$463 million in FY 2011.

Conclusion

ADHA appreciates the difficult task Appropriators face in prioritizing and funding the many meritorious programs and grants offered by the federal government. In addition to the items listed, ADHA joins other oral health organizations in support for continued funding of the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program established under the Ryan White HIV/AIDS Treatment and Modernization Act (\$19 million for FY 2011) as well as block grants offered by HRSA's Maternal Child Health Bureau (\$8 million for FY 2011).

ADHA remains optimistic about the positive impact that the oral health provisions contained in the Patient Protection and Affordable Care Act, signed into law just weeks ago, will have on access to oral health care services in the United States. ADHA remains a committed partner in advocating for meaningful oral health programming that makes efficient use of the existing oral health workforce and delivers high quality, cost-effective care.

STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM
SUBMITTED TO THE U.S. HOUSE OF REPRESENTATIVES - COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HHS, EDUCATION, AND RELATED AGENCIES

April 16, 2010

Summary of Requests: Summarized below are the Fiscal Year 2011 (FY 2011) recommendations of the nation's 36 Tribal Colleges and Universities (TCUs), covering three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

DEPARTMENT OF EDUCATION PROGRAMS:

A. Higher Education Act Programs:

- **Strengthening Developing Institutions:** Section 316 of HEA Title III-A, specifically supports TCUs through two separate grant programs: a) formula funded development grants, and b) competitive facilities/construction grants designed to address the critical facilities needs at TCUs. The TCUs request that the *Subcommittee appropriate \$36 million to support these two vital programs.*

- **TRIO Programs:** Retention and support services are vital to achieving the Administration's goal of having the highest percentage of college graduates globally by 2020. The President's FY 2011 Budget Request includes level funding for TRIO programs, which if ultimately enacted, will result in a decrease in the current level of program services. In addition to increasing Pell Grants, it is imperative that Congress bolster TRIO programs such as Student Support Services and Upward Bound so that low-income students are given the support necessary to persist in and, ultimately, complete their postsecondary courses of study. The TCUs support an increase in FY 2011 TRIO programs and technical assistance funding.

- **Pell Grants:** TCUs urge the Subcommittee to fund the Pell Grant program at the highest possible level.

B. Perkins Career and Technical Education Programs: Section 117 of the Carl D. Perkins Vocational and Technical Education Act provides funding for the operating budgets for the nation's two tribally controlled vocational institutions: United Tribes Technical College in Bismarck, North Dakota, and Navajo Technical College in Crownpoint, New Mexico. *AIHEC requests \$10 million for the two tribal colleges that are funded under this section. Additionally, TCUs strongly support the Native American Career and Technical Education Program (NACTEP) authorized under Sec. 116 of the Act.*

C. Relevant Title IX Elementary and Secondary Education Act (ESEA) Programs:

- **Adult and Basic Education:** Although federal funding for tribal adult education was eliminated in Fiscal Year 1996, TCUs continue to offer much needed adult education, GED, remediation and literacy services for American Indians, yet their efforts cannot meet the demand. *The TCUs request that the Subcommittee direct \$5 million of the Adult Education State Grants appropriated funding to make awards to TCUs to support their ongoing and essential adult and basic education programs.*

- **American Indian Teacher and Administrator Corps:** The American Indian Teacher Corps and the American Indian Administrator Corps offer professional development grants designed to increase the number of American Indian teachers and administrators serving their reservation communities. *The TCUs request that the Subcommittee support these programs at \$10 million and \$5 million, respectively.*

DEPARTMENT OF HEALTH and HUMAN SERVICES PROGRAM:

D. Tribal Colleges and Universities Head Start Partnership Program (DHHS-ACF): Tribal Colleges and Universities are ideal partners to help achieve the goals of Head Start in Indian Country. The TCUs are working to meet the mandate that Head Start teachers earn degrees in Early Childhood Development or a related discipline. *The TCUs request that a minimum of \$5 million be designated for the TCU-Head Start Partnership program, to ensure the continuation of current programs and the resources needed to expand participation to include additional TCU-Head Start Partnership programs.*

I. BACKGROUND ON TRIBAL COLLEGES AND UNIVERSITIES

Tribal Colleges and Universities are accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, TCUs provide essential high school completion (GED), basic remediation, job training, college preparatory courses, and adult education programs. TCUs fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public meeting places, and child and elder care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.

Tribal Colleges and Universities, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally-based institutions are best suited to help American Indians succeed in higher education. TCUs effectively blend traditional teachings with conventional postsecondary curricula. They have developed innovative ways to address the needs of tribal populations and are overcoming long-standing barriers to success in higher education for American Indians. Since the first TCU was established on the Navajo Nation just over 40 years ago, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to, and promoting achievement among, students who may otherwise never have known postsecondary education success.

II. JUSTIFICATIONS FOR FY 2011 APPROPRIATIONS REQUESTS FOR TCUs**A. Higher Education Act**

The Higher Education Act Amendments of 1998 created a separate section (§316) within Title III-A specifically for the nation's Tribal Colleges and Universities. Programs under Titles III and V of the Act support institutions that enroll large proportions of financially disadvantaged students and that have low per-student expenditures. Tribal colleges, which are truly developing institutions, are providing access to quality higher education opportunities to some of the most rural, impoverished, and historically underserved areas of the country. A clear goal of the Higher Education Act Title III programs is "to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU Title III program is specifically designed to address the critical, unmet needs of their American Indian students and communities, in order to effectively prepare them to succeed in a global, competitive workforce. *The TCUs urge the Subcommittee to appropriate \$36 million in FY 2011 for HEA Title III-A section 316, an increase of \$5.8 million over FY 2010, and to direct the Department to reserve a portion of the funds, as authorized, to award several competitive construction grants. These funds will afford these developing institutions the*

resources necessary to continue their ongoing grant programs, and address the needs of their historically underserved students and communities, as well as their substandard facilities and infrastructure issues.

Retention and support services are vital to achieving the Administration's goal of having the highest percentage of college graduates globally by 2020. The TRIO-Student Support Services program was created out of recognition that college access was not enough to ensure advancement and that multiple factors worked to prevent the successful completion of higher education for many low-income and first-generation students and students with disabilities. Therefore, in addition to increasing Pell Grants, it is critical that Congress also bolster student assistance programs such as Student Support Services so that low-income students have the support necessary to allow them to persist in and, ultimately, complete their postsecondary courses of study.

The importance of Pell Grants to TCU students cannot be overstated. U.S. Department of Education figures show that the majority of TCU students receive Pell Grants, primarily because student income levels are so low and our students have far less access to other sources of financial aid than students at state-funded and other mainstream institutions. Within the TCU system, Pell Grants are doing exactly what they were intended to do -- they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. *The TCUs urge the Subcommittee to fund this critical program at the highest possible level.*

B. Carl D. Perkins Career and Technical Education Act

Tribally-Controlled Postsecondary Career and Technical Institutions: Section 117 of the Perkins Act provides operating funds for two of our member institutions: United Tribes Technical College in Bismarck, North Dakota, and Navajo Technical College in Crownpoint, New Mexico. *The TCUs urge the Subcommittee to appropriate \$10 million for Sec. 117 of the Act.*

Native American Career and Technical Education Program: The Native American Career and Technical Education Program (NACTEP) under Sec. 116 of the Act reserves 1.25 percent of appropriated funding to support Indian vocational programs. *The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the continuation of much needed career and technical education programs being offered at TCUs.*

C. Greater Support of Indian Education Programs

American Indian Adult and Basic Education (Office of Vocational and Adult Education): This program supports adult basic education programs for American Indians offered by state and local education agencies, Indian tribes, agencies, and TCUs. Despite a lack of funding, TCUs must find a way to continue to provide basic adult education classes for those American Indians that the present K-12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. The number of students in need of remedial education before embarking on their degree programs is considerable at TCUs. There is a broad need for basic adult educational programs and TCUs need adequate funding to support these essential activities. *TCUs respectfully request that the Subcommittee direct \$5 million of the funds appropriated for the Adult Education State Grants to make awards to TCUs to help meet the ever increasing demand for*

basic adult education and remediation program services that exists on their respective reservations.

American Indian Teacher/Administrator Corps (Special Programs for Indian Children):

American Indians are severely underrepresented in the teaching and school administrator ranks nationally. These competitive programs are designed to produce new American Indian teachers and school administrators for schools serving American Indian students. These grants support recruitment, training, and in-service professional development programs for Indians to become effective teachers and school administrators and in doing so become excellent role models for Indian children. We believe that the TCUs are ideal catalysts for these two initiatives because of their current work in this area and the existing articulation agreements they hold with 4-year degree awarding institutions. *The TCUs request that the Subcommittee support these two programs at \$10 million and \$5 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.*

DEPARTMENT OF HEALTH AND HUMAN SERVICES/ADMINISTRATION FOR CHILDREN AND FAMILIES/HEAD START

Tribal Colleges and Universities (TCU) Head Start Partnership Program: The TCU-Head Start Partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. Graduates of these programs help meet the degree mandate for all Head Start program teachers. More importantly, this program has afforded American Indian children Head Start programs of the highest quality. A clear impediment to the ongoing success of this partnership program is the erratic availability of discretionary funds made available for the TCU-Head Start Partnership. In FY 1999, the first year of the program, some colleges were awarded 3-year grants, others 5-year grants. In FY 2002, no new grants were awarded. In FY 2003, funding for eight new TCU grants was made available, but in FY 2004, only two new awards could be made because of the lack of adequate funds. *The TCUs request that the Subcommittee direct the Head Start Bureau to designate a minimum of \$5 million, of the more than \$8.2 billion included in the President's FY2011 Budget Request for programs under the Head Start Act, for the TCU-Head Start Partnership program, to ensure that this critical program can be expanded so that all TCUs have the opportunity to participate in the TCU-Head Start Partnership program to benefit their respective tribal communities.*

Conclusion

Tribal Colleges and Universities are providing access to higher education opportunities to many thousands of American Indians and essential community services and programs to many more. The modest Federal investment in TCUs has already paid great dividends in terms of employment, education, and economic development, and continuation of this investment makes sound moral and fiscal sense. TCUs need your help if they are to sustain and grow their programs and achieve their missions to serve their students and communities.

Thank you again for this opportunity to present our funding recommendations. We respectfully ask the Members of the Subcommittee for their continued support of the nation's Tribal Colleges and Universities and full consideration of our FY 2011 appropriations needs and recommendations.

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STATEMENT
OF
THE AMERICAN LIVER FOUNDATION

PRESENTED
TO
THE UNITED STATES HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

BY
ALLAN WOLKOFF, M.D.
CHAIRMAN OF THE BOARD

WASHINGTON, D.C.

April 16, 2010

Mr. Chairman and Members of the Subcommittee, thank you for giving the American Liver Foundation the opportunity to provide testimony as the Subcommittee begins to consider funding priorities for Fiscal Year (FY) 2011. My name is Dr. Allan Wolkoff and I am the Chairman of the Board of Directors of the American Liver Foundation (ALF), a national voluntary health organization dedicated to the prevention, treatment and cure of hepatitis and other liver diseases through research, education and advocacy. I am also a Professor of Medicine and Chief of the Division of Hepatology at the Albert Einstein College of Medicine.

ALF has a nationwide network of divisions and provides information to 300,000 patients and families. Over 70,000 physicians, including primary care practitioners and liver specialists and scientists also receive information from ALF. The ALF Board of Directors is composed of scientists, clinicians, patients and others who are directly affected by liver diseases. Every year ALF handles over 100,000 requests for information, helping patients and their families understand their illnesses, informing them about available services, and showing them that there are knowledgeable and concerned individuals to assist them in every possible way.

Mr. Chairman, ALF joins the Ad Hoc Group for Medical Research Funding, a coalition of some 300 patient and voluntary health groups, medical and scientific societies, academic research organizations and industry, in recommending \$35 billion in funding for the National Institutes of Health in FY 2011. While the ALF recognizes the demands on our nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify increased funding levels for the NIH. To ensure that NIH's momentum is not further eroded, and to ensure the fight against diseases and disabilities that affect millions of Americans can continue, ALF supports \$35 billion for the NIH in FY 2011 and a minimum increase of 12% (\$235 million) for the National Institute for Diabetes and Digestive and Kidney Diseases and for liver disease research across all NIH Institutes.

In addition to the NIH, there are a number of programs within the jurisdiction of the subcommittee that are important to ALF including the Centers for Disease Control's Division of Viral Hepatitis and the Health Resources Services Administration. Mr. Chairman, our specific recommendations for these and other areas of interest are summarized in a table at the end of this statement.

RECOGNIZING THE LEADERSHIP OF THE SUBCOMMITTEE

Mr. Chairman, ALF appreciates your leadership and the leadership of this Subcommittee in supporting NIH in a time of fiscal austerity. Your leadership in supporting CDC and HRSA are also greatly recognized and appreciated. These programs are important to our shared goals of improving the public health response to the threats of hepatitis and liver disease and to increasing the rate of organ donation. We applaud the Committee's leadership in making progress in these important areas and to allocating increased funding to these programs during periods of fiscal austerity.

A NATIONAL STRATEGY FOR PREVENTION AND CONTROL OF HEPATITIS B AND C.

The ALF is very pleased that the Office of the Secretary has convened and established an inter-departmental task-force to address the public health challenge of viral hepatitis. This is an important step for the Department to take to develop a comprehensive response to the challenge of hepatitis. In January 2010, the Institute of Medicine released a groundbreaking report titled "*Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*" documenting the problem and highlighting a course of action to address it. ALF urges its review and consideration by the Task Force. ALF also urges the Committee to request an update from the Task Force of their recommendations and actions and further urges the Committee to review and address the chronic underfunding of viral hepatitis prevention programs within the Department, including the National Institutes of Health and the CDC's Division of Viral Hepatitis.

THE NATIONAL INSTITUTES OF HEALTH AND THE LIVER DISEASE RESEARCH ACTION PLAN

We depend upon the NIH to fund research that will lead to new and more effective interventions to treat people with liver diseases. The American Liver Foundation joins with the Ad Hoc Group for Biomedical Research and requests a funding level of \$35 billion for the National Institutes of Health in FY 2011.

We thank the Committee for their continued investment in NIH in FY 2010. Sustaining progress in medical research is essential to the twin national priorities of smarter health care and economic revitalization. With additional investment, the nation can seize the unique opportunity to build on the tremendous momentum emerging from the strategic investment in NIH made through the 2009 American Recovery and Reinvestment Act (ARRA). NIH invested those funds in a range of potentially revolutionary new avenues of research that will lead to new early screenings and new treatments for disease.

In FY 2009, NIH spent approximately \$651 million on liver disease research overall (ARRA and non-ARRA funds), and estimates that in FY 2010 \$635 million will be spent. This includes research for viral hepatitis, liver cancer, and a host of other liver diseases. An additional \$235 million (12% increase) for the National Institute of Diabetes and Digestive and Kidney Diseases, the Institute with lead on liver disease research, could make transformational advances in research leading to better treatments for people with liver disease. The ALF recommends that in FY 2011 the National Institute of Diabetes and Digestive and Kidney Diseases be funded at \$2,192,247,000 and that overall NIH funding total \$35 billion.

Mr. Chairman, in December of 2004, the NIDDK released the Liver Disease Research Action Plan outlining major research goals for the various aspects of liver disease. Working with the leading scientific experts in the field, the plan is organized into 16 chapters and identifies numerous areas of research important to virtually every aspect of liver disease, including: improving the success rate of therapy of hepatitis C; developing noninvasive ways to measure liver fibrosis; developing sensitive and specific means of screening individuals at high risk for early hepatocellular carcinoma; developing standardized and objective diagnostic criteria for major liver diseases and their grading and staging; and decreasing the mortality rate from liver disease. Each year, the plan is reviewed and updated. The ALF urges the Committee to provide adequate funding and policy guidance to NIH to urge continued implementation of the plan.

CDC'S DIVISION OF VIRAL HEPATITIS

The Division of Viral Hepatitis (DVH) is included in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the CDC, and is responsible for the prevention and control of viral hepatitis, a disease which impacts over 6 million Americans and often leads to liver cancer and liver failure. The DVH provides the scientific and programmatic foundation for the prevention, control and elimination of hepatitis virus infections in the U.S. and also assists the international public health community in these activities. DVH works with state and local health departments to provide the guidance and technical expertise needed to integrate hepatitis prevention services such as hepatitis A and B vaccine, hepatitis B and C counseling, and testing and referral to existing public health programs serving individuals at high risk.

DVH is currently funded at \$19.3 million, \$6 million less than its funding level in FY 2003, which does not allow for the provision of core prevention services. The ALF joins the hepatitis community and urges a FY 2011 funding level for the Division of Viral Hepatitis of \$50 million.

INCREASING THE SUPPLY OF ORGANS FOR DONATION

As the Subcommittee knows, even with advances in the use of living liver donors, the increase in the demand for livers needed for transplantation will continue to exceed the number available. The need to increase the rate of organ donation is critical. On April 9, 2010 there were 106,917 men, women and children on the national transplantation waiting list. Last year an average of 80 patients were transplanted each day; however a daily average of 18 patients died because the organ they needed did not become available in time to save them. The shortage of organs for donation can be positively impacted by healthcare professionals, particularly physicians, nurse, and physician assistants that are frequently the first to identify and refer a potential donor. These professionals also have an established relationship with the family members that weigh the option to donate their loved one's organs. In order to improve the knowledge and skills of the several key health professions, ALF requests funding to develop curriculum and continuing medical education programs for targeted health professions. To launch a new five year effort to improve the competency of health professionals to help meet the goal of increasing the number

or organs available for transplantation \$450,000 is requested for the United Network for Organ Sharing (UNOS) to be made available from within the Division of Health Professions set aside authority for technical assistance.

SUMMARY AND CONCLUSION

Mr. Chairman, again we wish to thank the Subcommittee for its past leadership. Significant progress has been made in developing better treatments and cures for the diseases that affects mankind due to your leadership and the leadership of your colleagues on this subcommittee. Significant progress has also similarly been made in the fight against liver disease. For FY 2011 we recommend a 12% increase for NIH above the level of the FY 2010 funding levels, with the level of liver disease research also increased by at least 12%. We also urge a \$50 million for the CDC's Division of Viral Hepatitis to strengthen the public health response to hepatitis and liver disease and a \$2 million increase to HRSA's Division of Transplantation, as well as \$450,000 for the Division of Health Professions to increase the rate of organ donation. Mr. Chairman, if this country is to maintain its leadership role in health maintenance, disease prevention, and the curing of diseases, adequate funding for NIH, CDC and HRSA is paramount. The ALF appreciates the opportunity to provide testimony to you on behalf of our constituents and yours.

ALF RECOMMENDATIONS FOR FISCAL YEAR 2010 FUNDING

NIH and the Liver Disease Research Action Plan

- \$35 billion for NIH overall and 12% increase for the National Institute of Diabetes and Digestive and Kidney Diseases;
- +\$25 million to implement the Liver Research Action Plan

CDC: National Hepatitis C Prevention Strategy, Public Health Information, HAV & HBV Vaccinations

- Fund the CDC's Division of Viral Hepatitis at \$50 million to strengthen the public health response to chronic viral hepatitis; and

HRSA: Expanding the supply of organs

- + \$450,000 for an organ donation curriculum development initiative at HRSA's Division of Health Professions


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FY 2011
American Lung Association
U.S. House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education
Department of Health and Human Services

Summary of Programs

Centers for Disease Control and Prevention (CDC)

Increased overall CDC funding – \$8.8 billion

- Funding CDC COPD Program – \$3 million
- Funding Healthy Communities – \$52.8 million
- Office on Smoking and Health – \$280 million
- Asthma programs – \$70 million
- Environment and Health Outcome Tracking – \$50 million
- Tuberculosis programs – \$220.5 million
- CDC Influenza preparedness – \$159.1 million
- NIOSH – \$364.3 million

National Institutes of Health (NIH)

Increased overall NIH funding -- \$35 billion

- National Heart, Lung and Blood Institute – \$3.514 billion
- National Cancer Institute – \$5.725 billion
- National Institute of Allergy and Infectious Diseases – \$5.395 billion
- National Institute of Environmental Health Sciences – \$779.4 million
- National Institute of Nursing Research – \$163 million
- National Center on Minority Health & Health Disparities – \$236.9 million
- Fogarty International Center – \$78.4 million

The American Lung Association is pleased to present our recommendations to the Labor, Health and Human Services, and Education Appropriations Subcommittee. The public health and research programs funded by this committee will prevent lung disease and improve and extend the lives of millions of Americans who suffer from lung disease.

The American Lung Association is the oldest voluntary health organization in the United States, with national offices and local associations around the country. Founded in 1904 to fight tuberculosis, the American Lung Association today fights lung disease in all its forms through research, advocacy and education.

A SUSTAINED AND SUSTAINABLE INVESTMENT

We thank the Chairman and the Committee for your leadership in healthcare reform and the priority paid to prevention and wellness. Mr. Chairman, the investments this committee makes can and will pay near term and long term dividends for the health of the American people and people everywhere.

Specifically, we want to highlight the need for the American Recovery and Reinvestment (ARRA) funds to be incorporated into base funding levels in order to sustain these critical investments, **particularly for the Center for Disease Control and Prevention's public health programs**. These investments in prevention and wellness are crucial to ensuring a healthier population and a reduction in healthcare costs. Chronic disease is a huge driver of cost and human suffering and incorporating the ARRA funds into the baseline will allow sustained investments in proven interventions like smoking cessation.

The U.S. must also **maintain its renewed commitment to medical research**. A growing, sustained, predictable and reliable investment in the NIH provides hope for millions afflicted with lung disease. While our focus is on lung disease research, we strongly support increasing the investment in research across the entire National Institutes of Health.

LUNG DISEASE

Each year, almost 400,000 Americans die of lung disease. Lung disease is America's number three killer, responsible for one in every six deaths. More than 35 million Americans suffer from a chronic lung disease. Each year lung disease costs the economy an estimated \$173 billion. Lung diseases include: lung cancer, asthma, chronic obstructive pulmonary disease (COPD), tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease and sarcoidosis.

IMPROVING PUBLIC HEALTH

The American Lung Association strongly supports investments in the public health infrastructure. In order for the CDC to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs to improve the health of all Americans, we strongly support increasing the overall CDC funding to \$8.8 billion.

We strongly encourage improved disease surveillance and health tracking to better understand diseases like asthma. We support an appropriations level of \$50 million for the Environment and

Health Outcome Tracking Network to allow federal, state and local agencies to track potential relationships between hazards in the environment and chronic disease rates.

We strongly support investments in communities to bring together key stakeholders to identify and improve policies and environmental factors influencing health in order to reduce the burden of chronic diseases. These programs lead to a wide range of improved health outcomes including reduced tobacco use. We strongly recommend at least \$52.8 million in funding for the Healthy Communities program to expand its reach to more communities.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Chronic Obstructive Pulmonary Disease, or COPD, is the fourth leading cause of death both in the U.S. and worldwide and is not decreasing as quickly as other leading causes of death. Yet, it remains relatively unknown to most Americans. COPD refers to a group of largely preventable diseases, including emphysema and chronic bronchitis that gradually limit the flow of air in the body. It has been estimated that 12.1 million patients have been diagnosed with some form of COPD and as many as 24 million adults may suffer from its consequences. In 2006, 120,970 people in the U.S. died of COPD. The annual cost to the nation for COPD in 2010 is projected to be \$49.9 billion. This includes \$29.5 billion in direct health care expenditures, \$8.0 billion in indirect morbidity costs and \$12.4 billion in indirect mortality costs. Medicare expenses for COPD beneficiaries were nearly 2.5 times that of the expenditures for all other patients.

Despite the enormity of this problem, COPD receives far too little attention at CDC or in health departments across the nation. The American Lung Association strongly supports the establishment of a national COPD program within CDC's National Center for Chronic Disease Prevention and Health Promotion with a specific line item of \$3 million for FY 2011 to create a comprehensive national action plan for combating COPD. Creating this plan will address the public health role in prevention, treatment and management of this disease. This must occur if the nation is to begin to address this critical public health problem.

Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Progress is being made with research on the genetic susceptibility underlying COPD. Research is also showing promise for reversing the damage to lung tissue caused by COPD. Despite these promising research leads, the American Lung Association believes that research resources committed to COPD are not commensurate with the impact COPD has on the U.S. and the world.

The American Lung Association strongly recommends that the NIH and other federal research programs commit additional resources to COPD research programs. We strongly support funding the National Heart, Lung and Blood Institute and its lifesaving lung disease research program at \$3.514 billion.

TOBACCO USE

Tobacco use is the leading preventable cause of death in the United States, killing more than 443,000 people every year. Smoking is responsible for one in five U.S. deaths. The direct health care and lost productivity costs of tobacco-caused disease and disability are also staggering, an estimated \$193 billion each year.

Given the magnitude of the tobacco-caused disease burden and how much of it can be prevented; the CDC Office on Smoking and Health should be much larger and better funded. Historically, Congress has failed to invest in tobacco control – even though public health interventions have been scientifically proven to reduce tobacco use, the leading cause of preventable death in the United States. This neglect cannot continue if the nation wants to prevent disease and promote wellness.

In light of new funds available from the *Patient Protection and Affordable Care Act* and the Committee's FY2010 request to OSH for a five-year plan to significantly reduce tobacco use in the U.S., the American Lung Association urges that a minimum of \$280 million be appropriated to CDC's Office on Smoking and Health for FY 2011.

LUNG CANCER

An estimated 364,996 Americans are living with lung cancer. During 2009, an estimated 219,440 new cases of lung cancer were diagnosed, and 158,664 Americans died from lung cancer in 2006. Survival rates for lung cancer tend to be much lower than those of most other cancers. Men have higher rates of lung cancer incidence than women. However, over the past 33 years, the lung cancer age-adjusted incidence rate has decreased 17 percent in males compared to an increase of 147 percent in females. Furthermore, African Americans are more likely to develop and die from lung cancer than persons of any other racial group.

Lung cancer receives far too little attention and focus. Given the magnitude of lung cancer and the enormity of the death toll, the American Lung Association strongly recommends that the NIH and other federal research programs commit additional resources to lung cancer. We support a funding level of \$5.725 billion for National Cancer Institute and urge more attention and focus on lung cancer.

ASTHMA

Asthma is a chronic lung disease in which the bronchial tubes become swollen and narrowed, preventing air from getting into or out of the lung. An estimated 38 million Americans have been diagnosed with asthma by a health professional. Approximately 23.3 million Americans currently have asthma, of which 12.7 million had an asthma attack in 2008. Asthma prevalence rates are over 42 percent higher among African Americans than whites. Studies also suggest that Puerto Ricans have higher asthma prevalence rates and age-adjusted death rates than all other racial and ethnic subgroups.

Asthma is expensive. Asthma incurs an estimated annual economic cost of \$20.7 billion to our nation. Asthma is the third leading cause of hospitalization among children under the age of 15. It is also one of the leading causes of school absences. The federal response to asthma has three components: research, programs and planning. We are making progress on all three fronts but more must be done.

We recommend that the National Heart, Lung and Blood Institute receive \$3.514 billion and the National Institute of Allergy and Infectious Diseases be appropriated \$5.395 billion, and that both agencies continue their investments in asthma research in pursuit of treatments and cures.

The American Lung Association also recommends that CDC be provided \$70 million in FY11 to expand its asthma programs. This funding includes state asthma planning grants, which leverage small amounts of funding into more comprehensive state programs.

INFLUENZA

Influenza is a highly contagious viral infection and one of the most severe illnesses of the winter season. It is responsible for an average of 226,000 hospitalizations and 36,000 deaths each year. Further, the emerging threat of a pandemic influenza is looming as the recently emerging strain of H1N1 reminded us. Public health experts warn that 209,000 Americans could die and 865,000 would be hospitalized if a moderate flu epidemic hits the U.S. To prepare for a potential pandemic, the American Lung Association supports funding the federal CDC Influenza efforts at \$156 million. We also support investments in influenza totaling \$45 million for the Food and Drug Administration (FDA), \$35 million for the National Institutes of Health (NIH), and \$66 million for the Office of the Secretary, as proposed in the President's budget.

TUBERCULOSIS

Tuberculosis primarily affects the lungs but can also affect other parts of the body. There are an estimated 10 million to 15 million Americans who carry latent TB infection. Each has the potential to develop active TB in the future. About 10 percent of these individuals will develop active TB disease at some point in their lives. In 2008, there were 12,904 cases of active TB reported in the U.S. While declining overall TB rates are good news, the emergence and spread of multi-drug resistant TB pose a significant threat to the public health of our nation. Continued support is needed if the U.S. is going to continue progress toward the elimination of TB. We request that Congress increase funding for tuberculosis programs at CDC to \$220.5 million for FY 2011.

CONCLUSION

The American Lung Association also would like to indicate our strong support for growth of additional institutes and programs that impact lung health. We strongly support a 12 percent across the board increase for NIH with particular emphasis on the National Heart, Lung and Blood Institute, the National Cancer Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, the National Center on Minority Health & Health Disparities and the Fogarty International Center.

Mr. Chairman, lung disease is a continuing, growing problem in the United States. It is America's number three killer, responsible for one in six deaths. Progress against lung disease is not keeping pace with other major causes of death and more must be done. The level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

April 12, 2010

The Honorable David Obey
Chairman
Labor, Health and Human Services, Education and Related Agencies Subcommittee
Appropriations Committee
United States House of Representatives
Washington, D.C. 20515

Dear Chairman Obey:

On behalf of the American Mosquito Control Association, I am writing to ask your assistance in maintaining \$26.7 million in funding for controlling vector-borne diseases including West Nile Virus under the FY2011 Labor, Health and Human Services, Education and Related Agencies Appropriations Bill.

The American Mosquito Control Association represents an international association of individuals and organizations interested in mosquito and other vector control. Our mission is to provide leadership, information, and education leading to the enhancement of public health and quality of life through the suppression of mosquitoes and other vectors.

Since 1999, there have been more than 29,000 documented cases of West Nile Virus (WNV) in the US. Almost 12,000 of those cases have involved West Nile Neuroinvasive Disease, the most severe form. It is estimated that 1.65 million people in the US have been infected with and 1,122 people have died from WNV since 1999. It is believed that west Nile virus will continue to intermittently produce local or regional epidemics resulting in thousands of human cases.

Since 2000, appropriated funds have been provided to the Centers for Disease Control for distribution to states to assist them in developing and sustaining public health infrastructure to reduce risk of WNV. These funds are used for surveillance and monitoring of mosquito populations and the presence of WNV, for virus testing, and for applied research. Many state public health agencies and state, county or municipal mosquito control programs depend upon these funds to contend with WNV, and have also utilized this support to develop capacity to deal with exotic diseases transmitted by insects that may be introduced into the country.

However, the President's budget recommendation for FY2011 eliminates all of the current \$26.7 million of this funding. Given the virulence of WNV, coupled with the fiscal strain already put on states due to various economic factors, we respectfully request that the Appropriations Committee resist elimination of any of this funding for FY2011. Any savings provided by eliminating this essential funding will be insignificant compared to the losses suffered if the mosquito vector populations that spread WNV are not adequately suppressed.

Thank you for your consideration of this urgent public health matter.

Sincerely,



David Brown, Chairman
American Mosquito Control Association
cc: Congressman Todd Tiahrt, Ranking Member

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Name: Michael R. Duenas, O.D.
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RE:

STATEMENT OF THE AMERICAN OPTOMETRIC ASSOCIATION

IN SUPPORT OF THE NATIONAL EYE INSTITUTE

TO:

THE HOUSE APPROPRIATIONS COMMITTEE LABOR-HHS-EDUCATION

SUBCOMMITTEE

Date: April 14, 2010

The American Optometric Association appreciates the opportunity to submit written testimony to the file of the hearing of the Labor, Health and Human Services, Education and Related Agencies Subcommittee of the House Appropriations Committee in support of increased funding for the National Eye Institute (NEI), of the National Institutes of Health (NIH).

The American Optometric Association represents over 38,000 practicing Doctors of Optometry across the Nation. Doctors of Optometry (ODs), defined as physicians under Medicare, are the nation's frontline providers of eye and vision care. Optometrists are eye care professionals who diagnose, treat & manage diseases, injuries and disorders of the eye, its adnexa and visual system.

Optometrists provide care for tens of millions of patients across the country, and in more than 3,500 communities, ODs are the only professional eye care providers. In addition to providing eye and vision care as part of a primary care team, optometrists play a major role in a patient's overall health and well-being by detecting and helping prevent complications of systemic diseases such as hypertension, cardiovascular disease, arthritis, thyroid disease, neurologic disease and endocrine disorders, including, diabetes, the leading cause of acquired blindness.

The American Optometric Association supports the goal of the National Eye Institute: to conduct research for new treatment and cures for eye diseases and visual disorders, and to preserve and protect sight. Since the NEI was founded in 1968, optometrists have been active participants in projects managed by the Institute, the results of which have improved the vision and eye health and quality of life for American citizens.

The AOA requests \$794.5 million for Fiscal Year (FY) 2011 for the National Eye Institute. We believe this funding is necessary in order for the NEI to fund vital research to prevent blindness and improve the quality of life for the public.

Vision and eye health problems are the second most prevalent, chronic, health care problem in the U.S. The National Eye Institute (NEI) estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020.

Visual disorders reduce the educability of children and hasten the loss of independence in the elderly. Visual disorders and disabilities impose billions in direct and indirect costs on our society each year. The annual economic and societal cost of vision impairment and eye disease among adults, estimated at \$51.4 billion in the United States, is significant and growing. Adequately funding the NEI is a cost-effective investment in our nation's health, as it can delay, save and prevent expenditures, especially to the vulnerable populations comprising the Medicare and Medicaid programs.

Finding potential cures for vision disorders and improving the translation of research to effective clinical care and prevention of eye diseases is essential to the health of our nation.

Fear of blindness is second only to fear of cancer among our nation's elderly. Vision and eye health problems increase significantly in frequency and severity with age and are a growing public health problem. Vision problems among the elderly are often a key reason for the abandonment of independent living and frequently require rehabilitative services. Not only is the prevalence of eye disease increasing due to the aging population, but also the incidence disproportionately affects minority populations and is a co-morbid condition of chronic disease, such as diabetes and arthritis.

By 2020, more than 50 million Americans will experience blindness, low vision or age-related eye disease. This trend can only be mitigated through ongoing NEI research and its effective and timely translation, through treatments and therapies, to clinical practice.

The NEI has conducted and supported research that has resulted in the early diagnosis and prompt treatment of eye diseases. Age related macular degeneration (AMD) is the most common cause of severe visual impairment in older Americans. Approximately 1.7 million older Americans have AMD-related decreased vision, and 100,000 are blind from the disease. While there is currently no cure for AMD, the NEI has conducted research to test new treatments including the effects of high antioxidants on the progression of AMD and cataracts. This research is on-going to follow the natural history and genetic predisposition for these conditions.

A related area of concern is low vision, which is broadly defined as any chronic visual condition that is not correctable by glasses or contact lenses that impairs everyday functioning. As many as 12 million Americans suffer from visual impairment which affects their ability to read, drive and work. The leading causes of low vision are diseases that are common among older adults: age-related macular degeneration (AMD), cataracts, glaucoma and diabetic retinopathy.

There are many areas in low vision in which further research is needed. One area that deserves particular mention is the advancement of technology and assistive devices to help those with visual impairments carry out everyday functions as independently as possible. Issues to explore include providing sufficient training in the use of these devices, reducing their cost, and improving the function and appearance of these devices. Scientists are researching better ways of presenting hard-to-read computer graphic user interfaces and are developing telescoping and other optical devices to improve intermediate distance tasks and peripheral vision.

The NEI has funded a landmark clinical trial, the Vision in Preschool Children (VIP) study which determined the screening tests most likely to identify preschool children in need of vision care for amblyopia ("lazy" eyes), refractive errors (e.g., nearsightedness or farsightedness) and binocular defects (eye coordination). With the identification of early development of vision conditions in children, treatment can prevent complications, which

can result in better school achievement and health outcomes leading to more productive and healthier lives across the lifespan.

The growth of the NEI budget should continue to permit the proper and full translation and integration of these research findings to effective preventive clinical services. The growth of the NEI budget should also reflect continued funding of grants in the areas of binocular vision, convergence insufficiency, amblyopia and refractive error, all of which demonstrate disproportionate burdens to the economically disenfranchised and ethnic minorities.

The value of clinical trials to the public cannot be overestimated. NEI has a remarkable record of scientific breakthroughs attributed to clinical trial research beginning with studies of diabetic retinopathy in the 1970s. By identifying the appropriate treatment for diabetic retinopathy to prevent the loss of vision, enough public dollars are saved each year to cover many times over the cost of treatment as well as the cost of conducting the trial. NEI clinical trials involve many institutions, hundreds of health professionals and thousands of patients, including representatives of sub-populations and must continue.

The NIH recognizes and the AOA supports research to eliminate racial and ethnic health disparities; however, despite the current efforts to provide vision care for children, there is considerable evidence of disparities in both the access and utilization of vision care from national and state population-based surveys as well as from studies in clinical or community settings. Being a child of an economically disenfranchised family compounds the risk of vision loss. Statistics amply demonstrate the disproportionately greater burden of disease, disability and death experienced by racial and ethnic minorities in this country. Racial and ethnic minorities in the United States have significantly higher rates of visual impairment due to refractive error and complications from diabetes, glaucoma, HIV/AIDS, and other diseases.

Optometric researchers are grateful for the commitment that Congress has demonstrated to the NEI and its mission. The investment made in eye/vision research has paid great dividends to the American people through major breakthroughs in vision and eye health care. Despite this, there is still much more to be done to preserve, protect and enhance vision and eye health for all Americans. We encourage this committee to continue its commitment to NEI and vision and eye health research by making healthy vision one of the top priorities within NIH by providing the \$794.5 million funding level recommended by the vision research community.



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OFFICIAL STATEMENT

**STATEMENT FOR THE RECORD
BY
AMERICAN PHYSICAL THERAPY ASSOCIATION**

**UNITED STATES HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED
AGENCIES**

**APPROPRIATIONS PRIORITIES FOR FISCAL YEAR 2011 WITHIN THE UNITED STATES
DEPARTMENT OF EDUCATION AND THE UNITED STATES DEPARTMENT OF HEALTH AND
HUMAN SERVICES**

APRIL 13, 2010

*(Submitted by: Nate Thomas – Associate Director of Federal Government Affairs, American Physical
Therapy Association, 703-706-8527, nate@thomas@apta.org)*

Chairman Obey and Members of the House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies:

On behalf of more than 74,000 physical therapists, physical therapist assistants, and students of physical therapy, the American Physical Therapy Association (APTA) thanks you for the opportunity to submit official testimony regarding recommendations for the Fiscal Year 2011 appropriations. APTA's mission is to improve the health and quality of life of individuals in society by advancing physical therapist practice, education, and research. Physical therapists across the country utilize a wide variety of federally funded resources to work collaboratively toward the advancement of these goals. APTA's recommendations for federal funding as outlined in this document reflect the commitment toward these priorities for the good of society and the rehabilitation community.

Department of Health and Human Services

National Institutes of Health (NIH)

Rehabilitation research was funded at \$404 million within NIH's approximately \$30.5 billion budget in FY 2009. This represents roughly 1% of NIH funds for an area of biomedical research that impacts a growing percentage of our nation's seniors, persons with disabilities, young persons with chronic disease or traumatic injuries, and children with development disabilities. The Institute of Medicine (IOM) estimates that 1 in 7 individuals have an impairment or

limitation that significantly limits their ability to perform activities of daily living. Investment in and recognition of rehabilitation within NIH is a necessary step toward continuing to meet the needs of these individuals in our population. Through the American Recovery and Reinvestment Act (ARRA), rehabilitation research has been able to take advantage of an extra infusion of approximately \$75 million in FY 2009. However, APTA believes that rehabilitation research at NIH has been under-funded for many years. The funds currently utilized are well-invested for the impact that rehabilitation interventions will have on the quality of lives of individuals. Continued investment and greater recognition and coordination of rehabilitation research among Institutes and across federal departments will enhance the returns the federal government receives when investing in this area. Taking this into consideration, **APTA advocates for \$35.2 billion (a \$4.2 billion increase over FY 2010) for NIH** to capitalize on the momentum achieved under the ARRA investment to improve health, spur economic growth and innovation, and advance science.

Specifically, the physical therapy and rehabilitation science community recommends that Congress allocate crucial funding enhancements in the following institutes:

- **\$1.5 billion (a 12.5% increase over FY 2010) for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)** which houses the National Center for Medical Rehabilitation Research (NCMRR), the only entity within NIH explicitly focused on the advancement of rehabilitation science. NCMRR fosters the development of scientific knowledge needed to enhance the health, productivity, independence, and quality-of-life of people with disabilities. A primary goal of the Center-supported research is to bring the health related problems of people with disabilities to the attention of the best scientists in order to capitalize upon the myriad advances occurring in the biological, behavioral, and engineering sciences.
- **\$1.857 billion (\$221 million increase over FY 2010) for the National Institute of Neurological Disorders and Stroke (NINDS).** This funding level is required to enhance existing initiatives and invest in new and promising research to prevent stroke and advance rehabilitation in stroke treatment. Despite being a major cause of disability and the number three cause of death in the U.S., NIH invests only 1% of its budget on stroke research. However, APTA recognizes the advancements that NIH-funded research has achieved in the specific area of stroke rehabilitation. APTA commends this area of leadership at NIH and encourages a continued focus on rehabilitation interventions and physical therapy to maximize an individual's function and quality of life after a stroke.
- **\$500 million in arthritis and musculoskeletal research within the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**

Centers for Disease Control and Prevention (CDC)

APTA was disappointed to see the cuts that have been proposed for CDC through the administration's FY 2011 budget proposal. The potential contributions of CDC to the lives of countless individuals are limited only by the resources available for carrying out its vital mission. Our nation and the world will continue to benefit from further improvement in public health and investment in scientific advancement and prevention. **APTA recommends Congress provide at least \$8.8 billion for CDC's FY 2010 "core programs" in the FY 2011 Labor-HHS-Education Appropriations bill.** This request reflects the support CDC will need to fulfill its core missions for fiscal year 2011. APTA strongly believes that the activities and programs supported by CDC are essential in protecting the health of the American people.

Physical therapists play an integral role in the prevention, education, and assessment of the risk for falls. The CDC is currently only allocating \$2 million per year to address the increasing prevalence of falls, a problem costing more than \$19.2 billion a year. Among older adults, falls are the leading cause of injury deaths. This is why **APTA respectfully requests that \$20.7 million be provided in funding for the “Unintentional Injury Prevention” account to allow CDC’s National Center for Injury Prevention and Control (NCIPC) to comprehensively address the large-scale growth of older adult falls.**

Currently, CDC’s program on arthritis receives \$13 million in annual funding, and about half of which is distributed via competitive grants to 12 states to deliver and promote proven arthritis intervention strategies. Physical therapy interventions are designed to restore, maintain, and promote maximal physical function for people with arthritis. **An additional investment of \$10 million, beginning in Fiscal Year 2011,** would fund up to 14 new states and bring evidence-based prevention programs to many more Americans through innovative delivery approaches.

Traumatic Brain Injury (TBI) is a leading cause of death and disability among young Americans and continues to be the signature injury of the conflicts in Iraq and Afghanistan. CDC estimates that at least 5.3 million Americans, approximately 2% of the U.S. population, currently require lifelong assistance to perform activities of daily living as a result of TBI. High quality, evidence-based rehabilitation for TBI is typically a long and intensive process. From the battlefield to the football field, American adults and youth continue to sustain TBIs at an alarming rate and funding is desperately needed for better diagnostics and evaluation, treatment guidelines, improved quality of care, education and awareness, referral services, state program services, and protection and advocacy for those less able to advocate for themselves. **APTA recommends at least \$10 million in FY 2011 for CDC’s TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention, and National Public Education/Awareness programs.**

APTA would like to see \$76 million (\$20 million increase over FY 2010) for CDC’s Heart Disease and Stroke Prevention Program in FY 2011. CDC spends on average only 16 cents a person each year on heart disease and stroke prevention, despite the fact that heart disease, stroke and other forms of cardiovascular disease remain our nation’s number one and most costly killer. A \$20 million increase in funding will allow CDC to support the 9 states that receive no funding for the competitively awarded Heart Disease and Stroke Prevention Program, elevate more states to basic program implementation, and support the other funded states.

CDC’s Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN) programs screens uninsured and under-insured low-income women ages 40 to 64 for heart disease and stroke risk and those with abnormal results receive counseling, education, referral and follow up. WISEWOMAN reached over 84,000 women and provided more than 210,000 lifestyle intervention sessions from 2000 to mid-2008, while also identifying 7,647 new cases of high blood pressure, 7,928 new cases of high cholesterol, and 1,140 new cases of diabetes. Among those WISEWOMAN participants who were re-screened one year later, average blood pressure and cholesterol levels had decreased considerably. **APTA recommends \$37 million (\$16.3 million increase over FY 2010) for CDC’s WISEWOMAN Program in FY 2011.**

Health Resources and Services Administration (HRSA)

Through the successful passage of health care reform legislation, it becomes more important now than ever that America is able to supply an adequate and well-trained health care workforce to meet the demands of an expanded market of U.S. citizens that have health insurance coverage. **APTA urges you to provide at least \$9.15 billion for HRSA in FY 2011.** This amount reflects the minimum amount necessary for the agency to adequately meet the needs of the populations they serve. The relatively level funding HRSA has received over the past several years has undermined the ability of its successful programs to grow and be expanded to represent professions that shape the entire health care team, such as physical therapy. Any shortage areas of physical therapists and rehabilitation professionals may become more accentuated as the percentage of the U.S. population that has health coverage increases and demand rises. It is beneficial to undertake efforts to strengthen the health care workforce and delivery across the whole spectrum of an individual's care – from onset through rehabilitation. More resources are needed for HRSA to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and health care infrastructure.

In conjunction with the importance of funding TBI efforts within CDC, **APTA also recommends \$8 million for the HRSA Federal TBI State Grant Program and \$4 million for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program**

Department of Education

In 2008, as part of the reauthorization of the Higher Education Act (PL 110-315), the Loan Forgiveness for Service in Areas of National Need (LFSANN) program was created. This program would provide a modest amount of loan forgiveness for a variety of education and health care professional groups, including physical therapists, upon a commitment to serve in targeted populations that were identified as areas of crucial importance and national need. However, the program has not been implemented because it has not received any funding. APTA commends the recent efforts of Congress to reform the higher education loan industry. The lowering of the limit on the income-based repayment plan for consolidated federal Direct Loans will assist the burdensome payments for all higher education loan borrowers. However, this program still fails to meet the most important impact of LFSANN – channeling providers and professionals into areas where there are demonstrated shortages and high need, such as physical therapy care for veterans and children and adolescents. **APTA strongly urges Congress to take action and provide \$10 million in initial funding for this vital LFSANN program that will impact the health care and education services of those most in need.**

National Institute for Disability and Rehabilitation Research (NIDRR)

NIDRR has been one of the longest standing agencies to focus on federally-funded medical rehabilitation research. Rehabilitation research makes a difference in the lives of individuals with impairments, functional limitations, and disability. Advancements in rehabilitation research have led to greater quality of life for individuals who have spinal cord injuries, loss of limb, stroke and other orthopedic, neurological, and cardiopulmonary disorders. Investment in NIDRR is a necessary step toward continuing to meet the needs of individuals in our population who have chronic disease, developmental disabilities or traumatic injuries. Therefore, **APTA**

recommends at least \$20 million per year for NIDRR to support research and development, capacity building, and knowledge translation in health, rehabilitation, and function.

APTA also requests \$11 million for NIDRR's TBI Model Systems administered by the Department of Education. The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine and rehabilitation care for this crucial and growing population.

Interagency Committee on Disability Research (ICDR)

APTA would like to see \$1.5 million appropriated for the Interagency Committee on Disability Research (ICDR) to support a research agenda-setting summit. The disability and rehabilitation research community feels that such a meeting would ultimately be beneficial to work cooperatively on strategies to leverage the federal investments in disability and rehabilitation research across all respective agencies and facilitate the conducting of meaningful collaborative projects and initiatives, including capacity building and knowledge translation.

In conclusion

APTA looks forward to working with the Subcommittee and the various agencies outlined above to advance the resources available for the rehabilitation needs of society. If the Subcommittee has questions or needs additional resources, please contact Nate Thomas, Associate Director of Federal Government Affairs at APTA, at natethomas@apta.org or 703-706-8527. Mailing address is provided on the letterhead of the first page of this document.

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The American Physiological Society Statement on FY 2011 Funding for the National Institutes of Health

The American Physiological Society (APS) thanks the Chairman and all the Members of this Subcommittee for their support for the National Institutes of Health (NIH). Research carried out by the NIH contributes to our understanding of health and disease, which allows all Americans to look forward to a healthier future. **In this testimony, APS recommends that the NIH be funded at \$37 billion in FY 2011.**

The APS is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has nearly 10,000 member physiologists. APS members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S.

Momentum from ARRA should be maintained at the NIH

The inclusion of \$10.4 billion for biomedical research in the American Recovery and Reinvestment Act of 2009 (ARRA) has provided the NIH with an unprecedented opportunity to move science forward. To date, the ARRA investment has funded over 14,000 scientific projects in all 50 states.¹

Last year the NIH moved quickly to take advantage of the opportunities provided by ARRA to address important areas of scientific need. ARRA funds are already being used to support new science in high priority areas such as biomarker discovery, regenerative medicine, stem cell research and translational science through the Challenge Grant program. ARRA funds are also being used to support highly meritorious research proposals that had gone unfunded due to years of slow growth in the NIH budget. In recent years, only 1 out of every 5 proposals submitted to the NIH received funding, leaving many important research questions unexplored. The ARRA funds have allowed NIH to direct funds to some of the most interesting and important projects that were unfunded for budgetary reasons. ARRA funds will also reach the next generation of scientists through hands-on summer research experiences for approximately 5,000 undergraduates and science educators.

As a result of the ARRA investment, the NIH estimates that 50,000 jobs nationwide will be created or retained.² The widespread distribution of NIH ARRA funds has already had a direct economic impact on the research community by funding labs and projects that would otherwise have gone unfunded. However, state and local economies also stand to benefit substantially from the stimulus funds being spent by NIH researchers. A report by Families USA showed that on

average in the year 2007, every dollar of NIH funding generated twice as much in state economic output.³

In order to capitalize and build on the functional capacity created through the ARRA investment, we urge Congress to make every effort to fund the NIH at a level of \$37 billion in FY 2011. Funding at this level takes into account the additional ARRA funds that have been added to the NIH budget, and allows for growth at the rate of the biomedical research and development price index (BRDPI). This will maintain the momentum created by ARRA and start the NIH on a new path of consistent and sustainable growth in future budget cycles.

NIH funds outstanding science

As a result of improved health care, Americans are living longer and healthier lives in the 21st century than ever before. However, diseases such as heart failure, diabetes, cancer and emerging infectious diseases continue to inflict a heavy burden on our population. The NIH invests heavily in basic research to explore the mechanisms and processes of disease. This investment results in new tools and knowledge that can be used to design novel treatments and prevention strategies. A key example comes from the recent outbreak of H1N1 flu. From the time that the first cases of the disease emerged, it took approximately six months to develop a vaccine, identify those most at risk and begin to understand how and why the H1N1 flu strain differs from those seen in an average year. The ability to rapidly respond to this and other threats to human health is directly dependent upon maintaining a robust scientific enterprise.

Last year the Nobel Prize in Physiology or Medicine was awarded to three longtime NIH grantees. Drs. Jack Szostak, Elizabeth Blackburn and Carol Greider shared the 2009 prize for their discovery of how the tips of chromosomes are protected from degradation during cell division. Since the discovery of this fundamental cellular mechanism, researchers have been able to apply this knowledge to better understand how cells age and why they sometimes become cancerous. Collectively NIH has supported their research for more than 30 years.⁴ Three other NIH grantees won the Nobel Prize in Chemistry in 2009. Drs. Venkatraman Ramakrishnan, Thomas A. Steitz and Ada E. Yonath identified the structure of the ribosome, the molecular machinery that makes proteins in cells. NIH has supported these researchers in their work for nearly four decades.⁵

NIH nurtures the biomedical research enterprise

In addition to supporting research, the NIH must also address workforce issues to ensure that our nation's researchers are ready to meet the challenges they will face in the future. The Administration's FY 2011 budget proposal includes funding for a 6% increase in stipend levels for National Research Service Awards (NRSA). The APS applauds this proposed increase and calls on Congress to make every effort to fully fund the request.

New investigators entering the scientific workforce have frequently encountered long training periods before gaining independence and funding for their own research labs. In FY 2007, the average age of new investigators receiving their first awards from NIH rose to 42 years. To address this problem and foster the next generation of scientists, the NIH has committed to funding new investigators at approximately the same rate as established investigators.⁶ This will allow investigators to become independent and able to explore innovative ideas at an earlier

stage of their careers. However, efforts will be successful only if funds are available to continue to support the careers of new and young investigators beyond the period of their first grant.

The NIH is also home to the Institutional Development Award (IDeA) Program. Established in 1993, the goal of the IDeA program is to broaden the geographic distribution of NIH funds by serving researchers and institutions in areas that have not historically received significant NIH funding. IDeA builds research capacity and improves competitiveness in those states through the development of shared resources, infrastructure and expertise. IDeA currently serves institutions and investigators in 23 states and Puerto Rico.

The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with \$37 billion in FY 2011 so that researchers can build on the momentum and capacity created through the ARRA investment.

¹ <http://report.nih.gov/recovery/arragrants.cfm>

² http://report.nih.gov/PDF/Preliminary_NIH_ARRA_FY2009_Funding.pdf

³ <http://www.familiesusa.org/assets/pdfs/global-health/in-your-own-backyard.pdf>

⁴ <http://www.nigms.nih.gov/News/Results/nobel20091005.htm>

⁵ http://www.nigms.nih.gov/News/Results/nobel_20091007a.htm

⁶ http://grants.nih.gov/grants/new_investigators/index.htm

Testimony Submitted for the Record
 To House Appropriations Subcommittee on Labor, HHS, Education
 By the American Psychological Association
 750 First Street, NE, Washington, DC 20002
 April 16, 2010

The American Psychological Association (APA), in Washington, D.C., is the largest scientific and professional organization representing psychology in the U.S., including more than 150,000 researchers, educators, clinicians, consultants and students. APA works to advance psychology as a science, as a profession and as a means of promoting health, education and human welfare. Below are APA's recommendations for the funding of programs in the Departments of Health and Human Services, and Education for Fiscal Year 2011.

APA supports the recommendations of the Ad Hoc Group for Medical Research Funding of \$35 billion for the National Institutes of Health, and of the Coalition for Health Funding which supports an increase of \$9.3 billion for all the agencies of the U.S. Public Health Service. The public health system requires additional support after years of underinvestment. We are concerned that our already fragile public health infrastructure lacks the capacity to support mounting health needs under the weight of an ongoing recession, an aging population, a health workforce shortage, and persisting declines in health status.

Department of Health and Human Services

Bureau of Health Professions, Graduate Psychology Education Program-- The APA requests that the Subcommittee include \$7 million for the Graduate Psychology Education Program (GPE) within the Health Resources & Services Administration. This nationally competitive grant program provides integrated health care services to underserved rural and urban communities and individuals most in need of mental and behavioral health support with the least access to these services (e.g., children, older adults, chronically ill persons, victims of abuse or trauma, including veterans). To date there have been 70 grants in 30 states to universities and hospitals throughout the nation. All psychology graduate students who benefited from GPE funds are expected to work with underserved populations and 34-100% will work in underserved areas immediately after completing the training.

Currently it is authorized under the Public Health Service Act [P.L. 105-392 Section 755 (b)(1)(J)] and funded under the "Allied Health and Other Disciplines" account in the Labor-HHS Appropriations Bill. Explicit authorizing legislation was introduced in the 1st Session of the 111th Congress in the U.S. Senate (S 811), as well as in the U.S. House of Representatives (HR 2066). The GPE Program has been included in the President's Budget for the past two years.

Established in 2002, GPE grants have supported the interdisciplinary training of over 2,500 graduate students of psychology and other health professions to provide integrated health care

services to underserved populations. *The FY 2011GPE funding request will focus especially on providing services to older adults, returning veterans, and the unemployed.* The GPE funding request will also be used to create training opportunities at our nation's Federally Qualified Health Centers, which play a critical role in meeting the health and mental/behavioral health care needs of underserved communities all across the country.

The GPE Program specifically seeks to address the needs of older adults. Approximately 20% of older adults have a mental health condition, such as depression, anxiety, alcohol, or substance abuse. In addition, studies show that substance abuse combined with depression makes older adults especially vulnerable to suicide (*Retooling for an Aging America*, IOM, 2008). Moreover, older adults with chronic illnesses such as heart disease have higher rates of depression than those who are physically healthy (APA, 2008). Rural areas have a greater percentage of older adults than urban areas, and older adults in rural communities have a higher incidence of chronic illnesses such as heart disease, diabetes, high blood pressure, and obesity than those in urban communities (Alliance for Health Reform, RWJ Foundation, January 2010).

Because of their extensive education and training, psychologists are uniquely qualified to address the needs of unemployed persons (e.g., assessing skills and interests for retraining; determining the emotional status of the individual; treating mental and behavioral health issues; and providing guidance for job searches, interviewing strategies and techniques). The issue of joblessness and unemployment is a serious problem for many families, including those of returning veterans. Job loss due to multiple deployments has become a serious issue for this population, especially in the current economy.

Office of the Secretary of HHS: *Office of Minority Health.* Recently enacted health care reform legislation creates an Office of Minority Health in the Centers for Disease Control and Prevention, the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration, the Agency for Healthcare Research and Quality and the Centers for Medicare and Medicaid Services. APA urges Congress to ensure that these offices have sufficient funding to carry out their mission and to encourage the Secretary to provide full support to them.

Center for Substance Abuse Prevention, *Substance Use and Mental Disorders of Persons with HIV--*HIV-positive individuals who have co-occurring mental health and substance use disorders rarely receive "integrated" care with a treatment plan for all three disorders. APA recommends that Congress urge HRSA and SAMHSA to collaborate to expand the availability of the integrated care model. An integrated approach to HIV/AIDS care, mental health support and substance abuse treatment can improve patient adherence and lead to more favorable health outcomes for people living with HIV/AIDS.

Emergency Mental Health and Traumatic Stress Services Branch, *Child Trauma*-- SAMHSA has made significant efforts in the area of trauma through the outstanding National Child Traumatic Stress Network program and its coordinating center, the UCLA-Duke University National Center for Child Traumatic Stress. APA urges full funding for the National Child Traumatic Stress Initiative at the authorized level of \$50 million for FY 2011. Also, APA recommends the Committee to encourage SAMHSA to expand the duration of NCTSI grant awards from 3 years to 6 years.

Centers for Disease Control and Prevention, National Center for Health Statistics, *Sexual and Gender Identity Inclusion in Health Data Collection*-- The National Health Interview Survey (NHIS) is the most comprehensive and widely referenced federal health statistics survey, yet currently does not include any question concerning sexual orientation and gender identity. APA recommends the allocation of an additional \$2 million in funding for NHIS in the NCHS budget, to cover the cost of adding a sexual orientation/gender identity question to the survey. This would enable government agencies to better understand and plan for the unique health needs of lesbian, gay, bisexual, and transgender individuals.

CDC, National Center for Injury Prevention and Control, *Youth Violence Prevention*-- APA supports CDC's efforts to foster innovation in evidence-based youth violence prevention strategies through its Striving to Reduce Youth Violence Everywhere program. Recent, high-profile incidents have highlighted youth violence as a significant public health concern and homicide as the second leading cause of death among individuals age 10-24.

Community Health Centers (CHCs), *Child Maltreatment Prevention*-- APA recommends the implementation of at least 10 demonstration projects of evidence-based preventative parenting programs through CHCs. Technical assistance to demonstration sites should be provided by organizations with expertise in parent-child relationships, parenting programs, prevention of child maltreatment, and the integration of behavioral health in primary and community health center settings. APA recommends evaluating the demonstration projects' implementation and outcomes, including health and mental health outcomes, cost effectiveness, patient satisfaction, program local adaptation, improvement of parent-child relationship, child and family functioning, and reduction of child maltreatment and injuries. APA also supports education, recruitment, and training of mental health and primary care providers to implement culturally informed preventative programs that enhance parenting practices and screenings at the centers.

Administration for Children and Families, *Healthy Media for Youth*--. Research links sexualization with three of the most common mental health problems of female children, adolescents, and adults: eating disorders, depression or depressed mood, and low self-esteem.

APA encourages HHS to fund media literacy and youth empowerment programs to prevent and counter the effects of the sexualization of female children, adolescents, and adults.

Strengthening Families-- APA encourages ACF to continue its support of research programs that aim to strengthen families with economic hardship using empirically supported skills-based approaches. These projects aim to teach proven family strengthening skills and principles such as relationship education, stress management, and child-centered parenting to promote healthy inter-parental relationships that lead to healthy, well-functioning children. This research is critical to mitigating poverty and its impact on the health and well-being of individuals across the lifespan.

National Institutes of Health (NIH), behavioral research-- Understanding the complex influences of behavior on health is a critical part of NIH's mission. There is strong evidence that half of all deaths in the U.S. can be attributed to behavioral factors such as smoking, poor diet, substance abuse and physical inactivity. In addition, behavioral and social factors contribute to the staggering costs of preventable morbidity and mortality. NIH-supported behavioral and social sciences research ranges from basic research on memory, learning and perception, to prevention research, to clinical trials and comparative effectiveness research.

NIH, Office of Behavioral and Social Sciences Research--OBSSR was authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995. OBSSR develops, coordinates, and facilitates social and behavioral science research agenda at NIH; advises the NIH director and directors of the 27 Institutes and Centers; informs NIH and the scientific and lay publics of social and behavioral science research findings and methods; and trains scientists in the social and behavioral sciences. For FY 2011, APA supports a budget of \$41.32 million for OBSSR commensurate with the Administration's request of \$38.2 million for the Office and the scientific community's request for the NIH as a whole.

NIH, Office of Behavioral and Social Sciences Research, Basic Behavioral and Social Sciences Research--APA is pleased that NIH has established a initiative to increase and coordinate trans-NIH support for basic behavioral and social sciences research. Coordinated by OBSSR with leadership and contributions from multiple NIH institutes, the ***Opportunity Network for Basic Behavioral and Social Sciences Research (OppNet)***, will fund basic research to help fill gaps in knowledge about fundamental mechanisms and patterns of behavioral and social functioning, relevant to health and well-being, as they interact with each other, with biology and the environment.

NIH, National Institute on Minority Health and Health Disparities, Health Disparities--. The recent health care reform legislation elevated the National Center on Minority Health and

Health Disparities within NIH, giving it greater authority to address the health disparities that exist in minority communities. The Director of NIMHD is the primary federal official with responsibility for coordinating research and activities conducted or support by NIH on minority health and health disparities. APA recommends that Congress provides sufficient funding for NIMHD to carry out its mandated function and urges Congress and to support NIMHD in addressing priority health conditions of minority populations.

NIH, Behavioral Research Highlights—the following areas of NIH-supported research are good examples of the breadth and vitality of the behavioral research portfolio at NIH:

NIH Roadmap, Science of Behavior Change -- By focusing basic research on the initiation, personalization, and maintenance of behavior change, and by integrating work across disciplines, this Roadmap effort and subsequent trans-NIH activity could lead to an improved understanding of the underlying principles of behavior change, and drive a transformative increase in the efficacy, effectiveness, and (cost) efficiency of many behavioral interventions.

NIMH, Children's Mental Health—Early diagnosis, prevention and treatment is critical for the millions of families affected by autism, attention deficit hyperactivity disorder, anxiety disorders, depression, bipolar disorder and eating disorders. NIMH is supporting important clinical trials to demonstrate the evidence base for effective pharmacological and behavioral interventions treatments for child and adolescent populations with these disorders.

NIDA, Tobacco Addiction -- While significant declines in smoking have been achieved in recent decades, too many Americans, particularly youth, remain addicted to tobacco products. NIDA-supported researchers are identifying genetic and environmental factors that contribute to nicotine dependence and affect the efficacy of smoking cessation treatments.

Department of Education

National Institute on Disability and Rehabilitation Research: Disability Research-- APA recommends that NIDRR pursue mental health-related research proposals through its investigator-initiated and other grants programs, including sponsoring studies that will demonstrate the impact of socio-emotional, behavioral and attitudinal aspects of disability. APA encourages initiatives that support a broad field of NIDRR research, including Health and Functioning, Community Integration and Employment which will address societal barriers, such as stigmatization and discrimination, and their impact on people with physical, mental and neurological disabilities.

APA appreciates the opportunity to submit testimony for the record. Please contact Patricia Kobor in the Science Government Relations Office (pkobor@apa.org, 202/336-5933) with questions about this statement.



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Protect. Prevent. Live Well.

Testimony of the American Public Health Association
Concerning the Public Health Service Budget for Fiscal Year 2011
Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and
Human Services and Education
Submitted by: Donald Hoppert, Director of Government Relations
(202)777-2514 or donald.hoppert@apha.org

April 16, 2010

The American Public Health Association (APHA) is the oldest and most diverse organization of public health professionals and advocates in the world dedicated to promoting and protecting the health of the public and our communities. We are pleased to submit our views on federal funding for public health activities in fiscal year (FY) 2011.

Recommendations for Funding the Public Health Service

APHA's budget recommendations for the Public Health Service includes funding for the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH), as well as agencies outside the Subcommittee's jurisdiction—the Food and Drug Administration (FDA) and the Indian Health Service (IHS). Together all of these agencies play a critical role in keeping Americans healthy and each agency will also play a role in

CDC

APHA believes that Congress should support CDC as an agency—not just the individual programs that it funds. We support a funding level for CDC that enables it to carry out its mission to protect and promote good health and to assure that research findings are translated into effective state and local programs.

In the best judgment of APHA—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, injury, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs, and our many unmet public health needs and missed prevention opportunities—we believe the agency will require funding of at least **\$8.8 billion for CDC's "core programs" in FY 2011**. This request does not include the mandatory funding provided for the Vaccines for Children Program (VFC).

APHA appreciates the Subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, and environmental health programs at CDC. We also appreciate the support you provided in the economic recovery legislation for public health and prevention and wellness funding. By

translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. Ensuring a strong CDC is especially important given the important role CDC will play as the nation moves forward with implementing the strong public health and prevention provisions contained in the historic health reform legislation recently signed by President Obama.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak. This has been demonstrated most recently by CDC's quick response and ongoing investigation into human infections with H1N1 flu (swine flu) in the United States and internationally.

Unfortunately, the president's budget proposal for CDC would actually cut CDC's core programs by more than \$130 million from the FY 2010 enacted level. We must make up the lost ground and fully fund CDC's core public health programs at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

Public health programs delivered at the state and local level should be flexible to respond to state and local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services (PHHS) Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. We greatly appreciate the Subcommittee's past support for this program and we urge your continued support so that states can tailor federal public health dollars to meet their specific needs.

Injuries are the leading causes of death for persons aged 1-44 years. Unintentional injuries and violence such as older adult falls, unintentional drug poisonings, child maltreatment and sexual violence accounts for over 35% of emergency department visits annually with nearly 30 million people being treated in U.S. emergency departments each year. Annually, injury and violence ultimately cost the United States approximately \$406 billion in direct and indirect medical costs including lost productivity. The consequences of these injuries can be far reaching from physical, emotional, financial turmoil to long term disability. Though these facts paint a grim picture, current research shows that injuries are entirely preventable.

CDC's Injury Center works to prevent unintentional and violence-related injuries to minimize the consequences of injuries when they occur by researching the problem; identifying the risk and protective factors; developing and testing interventions; and ensuring widespread adoption of proven strategies. We urge you to include increased funding for CDC's injury programs.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. APHA members are committed to ending the disparities. We encourage the Subcommittee to provide \$60 million for CDC's REACH program.

We also encourage the Subcommittee to provide adequate funding for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local level. The agencies that carry out these services are fragmented and their resources are stretched. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, E. coli and lead in drinking water. We encourage the Committee to provide \$63 million for CDC's Environmental Health Laboratory and \$50 million for the National Environmental Health Outcome Tracking Network. We ask that the Subcommittee continue its recent efforts to expand and enhance CDC's capacity to help the nation prepare for and adapt to the potential health effects of climate change by providing CDC with \$50 million for climate change and health activities. Expanded funding would allow CDC to provide technical assistance, training and tools to help state and local health officials; conduct needs assessment to inform strategic planning; translate surveillance and research on climate-related diseases into methods and best practices to inform state and local health officials; and improve coordination and integration of climate change across CDC.

HRSA

Through its programs in every state and thousands of communities across the country, HRSA is a national leader in providing health services for individuals and families throughout the country and serves as a health safety net for the medically underserved including the 86.7 million Americans who were uninsured for some or all of 2007-2008 and 50 million Americans who live in neighborhoods where primary health care services are scarce. To respond to this challenge, APHA believes the agency will require an overall funding level of at least **\$9.15 billion in FY 2011**. This request is based on the authorized amounts and estimated needs of HRSA's various programs.

For several years, HRSA has suffered from relatively level funding, undermining the ability of its successful programs to grow. Our request reflects the minimum amount necessary for HRSA to adequately meet the needs of the populations they serve in FY 2011, especially during these difficult economic times that are causing an increase in demand for HRSA programs and funding. Much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services for all; eliminating health disparities; and rebuilding the public health and health care infrastructure.

APHA recommends \$600 million for health professions and nursing programs under Title VII and VIII of the Public Health Service Act. These programs are essential components of the nation's health care safety net, bringing health care services to our underserved communities, supporting the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit

organizations, the Title VII and VIII programs are the only federal programs designed to train providers in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

We also urge your support for an appropriation of \$730 million for the Title V Maternal and Child Health (MCH) Services Block Grant. This funding is needed to enable states to provide vital public health and health care services to millions of pregnant women, infants and children, including those with special health care needs. As the only Federal program that focuses solely on improving the health of all mothers and children, the MCH Block Grant provides a wide range of health services and fosters the prevention of disease and disabling conditions. State health agencies use MCH Block Grant funds to reduce infant mortality, provide women with prenatal and postnatal care, screen newborns for genetic and hereditary conditions, support expansion of medical homes, and prevent childhood injuries. Block grant funds also allow states to address critical needs including the training of health professionals, development of comprehensive systems for community-based services, and the testing and evaluation of innovative practices.

The Office of Rural Health Policy promotes better health services for the 60 million Americans who live in rural communities. These communities suffer from inadequate access to quality health services and experience the higher rates of illness associated with lower socioeconomic status. Rural Health Outreach and Network Development Grants, and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas. In addition, Rural Health Research Centers help policymakers better understand the challenges that rural communities face in assuring access to health services and improving the health of their residents. APHA encourages the Subcommittee to adequately fund these important programs that address the many unique health service needs of rural communities.

We urge the Subcommittee to support adequately funding all of HRSA's broad health programs and ensure that vulnerable populations transition smoothly into a new health system and receive continued, quality health services. By supporting, planning for and adapting to change, we can build on the successes of the past and address the new gaps that emerge as a result of health system reform.

AHRQ

We request a funding level of at least \$611 million for AHRQ for FY 2011. This level of funding is needed for the agency to fully carry out its Congressional mandate to conduct, support, and disseminate research and translate research into knowledge and information that can be used to improve the health of all Americans. AHRQ focuses on improving health care quality, eliminating racial and ethnic disparities in health, reducing medical errors, and improving access and quality of care for children and persons with disabilities.

SAMHSA

APHA supports a funding level of \$3.932 billion for SAMHSA for FY 2011. This funding level would provide support for substance abuse prevention and treatment programs, as well as continued efforts to address emerging substance abuse problems in adolescents, the nexus of substance abuse and mental health, and other serious threats to the mental health of Americans.

NIH

APHA supports a funding level of \$35 billion for the NIH for FY 2011. The translation of fundamental research conducted at NIH provides some of the basis for community based public health programs that help to prevent and treat disease.

FDA

While understanding the FDA is funded through the Agriculture Subcommittee, given the agency's public health mission, we want you to be aware of our support for a funding level of \$2.508 billion for FY 2011. It is essential that we provide FDA with the resources it needs to assure the safety of our food and the safety and efficacy of drugs and medical devices.

IHS

APHA supports adequately funding IHS so that health care programs accessed by American Indian/Alaska Native are funded at levels equal to the rest of the nation's citizens. In order to adequately reduce the health disparities and meet the health needs of the nation's American Indian/Alaska Native people, APHA urges the Subcommittee to provide \$4.82 billion for IHS for FY 2011.

Conclusion

In closing, we emphasize that the public health system requires stronger financial investments at every stage. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes, and other interventions that are effective and available for everyone. This is especially critical given the important role that CDC, HRSA and other public health agencies and programs will likely play as Congress works to reform the nation's health system.



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**Statement
Of the
AMERICAN PUBLIC POWER ASSOCIATION
Submitted to the
HOUSE APPROPRIATIONS COMMITTEE'S
SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES
March 24, 2010**

The American Public Power Association (APPA) is the national service organization representing the interests of over 2,000 municipal and other state and locally owned utilities throughout the United States (all but Hawaii). Collectively, public power utilities deliver electricity to one of every seven electricity consumers (approximately 45 million people), serving some of the nation's largest cities. However, the vast majority of APPA's members serve communities with populations of 10,000 people or less.

We appreciate the opportunity to submit this statement supporting funding for the Low-Income Home Energy Production Assistance Program (LIHEAP) for Fiscal Year (FY) 2011.

APPA has consistently supported an increase in the authorization level for LIHEAP. The Administration's FY 2011 budget requests \$3.3 billion for LIHEAP. APPA supports a level of \$5.1 billion for the program.

APPA is proud of the commitment that its members have made to their low-income customers. Many public power systems have low-income energy assistance programs based on community resources and needs. Our members realize the importance of having in place a well-designed low-income customer assistance program combined with energy efficiency and weatherization programs in order to help consumers minimize their energy bills and lower their requirements for assistance. While highly successful, these local initiatives must be coupled with a strong LIHEAP program to meet the growing needs of low-income customers. In the last several years, volatile home-heating oil and natural gas prices, severe winters, high utility bills as a result of dysfunctional wholesale electricity markets and the effects of the economic downturn have all contributed to an increased reliance on LIHEAP funds.

Also when considering LIHEAP appropriations this year, we encourage the Subcommittee to provide advanced funding for the program so that shortfalls do not occur in the winter months during the transition from one fiscal year to another. LIHEAP is one of the outstanding examples

of a state-operated program with minimal requirements imposed by the federal government. Advanced funding for LIHEAP is critical to enabling states to optimally administer the program.

Thank you again for this opportunity to relay our support for increased LIHEAP funding for FY 2011.



Testimony
Submitted for the Record

United States House of Representatives
Appropriations Committee
Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Fiscal Year 2011 Funding for Digestive Disease Research and
Colorectal Cancer Screening, Awareness, and Education

April 16, 2010

Presented by

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The American Society for Gastrointestinal Endoscopy (ASGE) is an 11,000-member, professional medical society whose mission is to advance patient care and digestive health by promoting excellence in gastrointestinal endoscopy. ASGE is the foremost resource for endoscopic education and promotes the highest standards for endoscopic training and practice, fosters endoscopic research, and recognizes distinguished contributions to endoscopy. The ASGE submits for the record this statement in support of FY 2011 funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and for the Centers for Disease Control and Prevention's (CDC) Colorectal Cancer Control Program.

Digestive Disease Research

In 2004, more than 236,000 American deaths were attributed to digestive diseases, which represented 9.8 percent of all deaths occurring in the United States.¹ While some digestive diseases, like colorectal cancer, can be fatal, the impact of these diseases ranges from the inconvenience of diarrheal disease, to chronic and debilitating illnesses requiring continuous medical care. In 2004, there were an estimated 72 million ambulatory care visits with a first-listed diagnosis of a digestive disease and more than 104 million visits with an all-listed diagnosis. To put these figures into perspective, for every 100 U.S. residents, there were 35 ambulatory care visits at which a digestive disease diagnosis was made.²

The cost of digestive disease in the United States is estimated to be \$141.8 billion,³ of which 69 percent is attributed to direct costs. This total cost likely is underestimated because it only includes non-Federal hospitals and physicians.⁴ Despite progress in reducing the burden of digestive disease in the United States, the cost and prevalence of digestive diseases warrant a proportionate investment in research through the NIDDK. The ASGE asks the Subcommittee to fund the NIDDK at \$2.05 billion for FY 2011, an increase of \$244 million.

Endoscopy is the use of a flexible instrument passed either through the mouth or the anus to observe, image, diagnose, and treat patients with digestive disorders. Colonoscopy is the best example of a procedure that was available for decades before it became widely used for colorectal cancer screening in the United States. The data now clearly show a cost-effective reduction in the incidence of colorectal cancer in Americans, which can be attributed directly to this clinical effort. With the proper resources and appropriate development, other endoscopic techniques will prove to have similar significant impact on the course of digestive diseases in Americans. Benign and malignant diseases of the esophagus, gallbladder, stomach, liver and pancreas are but a few examples of digestive diseases diagnosed and treated by endoscopy.

Evidence-based research is the foundation for the clinical guidelines that direct physician practice. As the health care delivery landscape continues to shift, the ASGE will rely on federally funded research to develop documents that set the standard for endoscopic care and guide the practice of its members. While basic science will drive new discoveries, there is also a

¹ *The Burden of Digestive Disease in the United States*. US Government Printing Office, 2008; NIH Publication No. 09-6443, p.2.

² 2004 is the last year for which data were available from all sources used in the analysis conducted for *The Burden of Digestive Diseases in the United States*.

³ *The Burden of Digestive Disease in the United States*. US Government Printing Office, 2008; NIH Publication No. 09-6443, p.140.

⁴ Federal hospitals and physicians include those of the armed services, Department of Veterans Affairs, and the Indian Health Service.

pressing requirement for research that will help physicians, in consultation with their patients, make better medical decisions. This need in the field of gastroenterology was made evident in the Institute of Medicine's (IoM) list of 100 initial priority topic recommendations for comparative effectiveness research,⁵ which was published in 2009 as mandated in the American Recovery and Reinvestment Act.

In the first quartile of research priorities, the IoM specifically identified a need for more comparative effectiveness research in upper endoscopy utilization and frequency for patients with gastroesophageal reflux disease, which includes associated conditions such as Barrett's esophagus and esophageal adenocarcinoma; studies on the effectiveness of different strategies of introducing biologics into the treatment algorithm for Crohn's disease and ulcerative colitis; and studies comparing the effectiveness of imaging technologies in diagnosing, staging, and monitoring patients with cancer, which would include endoscopic modalities such as colonoscopy and endoscopic ultrasonography.

The IoM included among the second quartile of priorities a need for comparative effectiveness studies of new screening technologies (such as fecal immunochemical tests and computed tomography colonography) and usual care (fecal occult blood tests and colonoscopy) in preventing colorectal cancer. This need was underscored by the U.S. Preventive Services Task Force (USPSTF), which identified important gaps in the understanding of optimal colorectal cancer screening strategies.⁶ The USPSTF specifically cited a need for higher-quality data about the natural history of small colonic adenomas, the importance of detecting flat adenomas, information about the age-specific and biopsy-related harms of colonoscopy, and systems approaches to promoting the use of colorectal cancer screening, among others.

Recognizing that comparative effectiveness research holds promise for cost savings to our health care system, President Obama and leaders within his Administration have identified this area of research as a national priority. The ASGE is pleased that the Patient Protection and Affordable Care Act (P.L. 111-148) establishes a Patient-Centered Outcomes Research Institute. While the ASGE agrees that a streamlined federal approach to comparative effectiveness research is needed, institutes such as the NIDDK should continue to play a vital role in helping to identify knowledge gaps in medicine and should play a central role in conducting comparative effectiveness research. Comparative effectiveness research represents a new focus for a large segment of the country's research establishment, and as such it will require a major investment in getting such studies launched and maintained, thereby necessitating an increased commitment of federal funding.

The Senate report language that accompanied the FY 2010 Labor, Health and Human Services and Education Appropriations bill included acknowledgement of a need for research into the use of endoscopic methods for treating obesity, recognizing the overwhelming economic burden that obesity places on our nation's health care system. We believe it is important to again underscore the critical need for NIDDK-sponsored research in this area. The endoscopy community is actively researching less invasive, and therefore less risky, highly effective alternatives to

⁵ *Initial National Priorities for Comparative Effectiveness Research*. Institute of Medicine, June 30, 2009.

⁶ *Screening for Colorectal Cancer: U.S. Preventive Services Task Force Recommendation Statement*. *Ann Intern Med*. 2008;149:627-637

bariatric (obesity) surgery. One of the exciting new developments is the ability to suture within the stomach using endoscopy (a camera passed through the mouth and into the stomach). In this novel technique, the endoscope's suturing is used to narrow the stomach, replicating steps taken during a more invasive operation called a vertical banded gastroplasty. Another area of research includes the endoscopic placement of a temporary sleeve between the stomach and small intestine, bypassing a key portion of intestine where food would otherwise trigger the release of hormones that regulate digestion. This minimally invasive procedure attempts to mimic gastric bypass surgery. Endoscopic bariatric researchers are also investigating the use of an endoscopically placed intragastric device that limits patients' sense of hunger. As in all fields of medicine, the rapid growth of technology has opened up tremendous opportunities for endoscopists to treat patients in less invasive and less costly ways. Because weight loss can lead to improved management or aversion of other debilitating and life-threatening conditions, such as diabetes, heart disease, and cancer, the ASGE believes that this field of research is critically important and warrants increased funding to the NIDDK.

Pancreatic cancer is the fourth most common cause of cancer death in the United States. It is the second leading cause of death from cancer of the digestive system, second only to colorectal cancer. Unlike colorectal cancer, however, pancreatic cancer has one of the worst prognoses of any cancer with an overall five-year survival rate less than 5 percent. Most patients will die of this disease within the first two years after diagnosis. The major reason for this dismal prognosis is due in large part to the advanced stage of the disease at diagnosis. The only known method to improve the outcome of this deadly disease is to improve methods for screening and early detection. At the present time, there is no widely available or effective screening test for pancreatic cancer and the search for such a test suffers from a lack of federally directed resources.

It is important to point out that in the past, many areas of research, including digestive disease research, have received financial support from pharmaceutical, device, and imaging industries. However, a radical departure is occurring, away from academic medical centers' reliance on industry support. Most major academic institutions now have strict policies limiting interactions with industry, and financial support is becoming much more difficult for researchers in need of funding to justify. While the academic institutions' new mandates are in response to policy makers who have expressed strong concerns about academic-industry ties, it has created a funding vacuum that will impose a greater burden on the National Institutes of Health, the CDC, the Agency for Healthcare Research and Quality, and other federal funding agencies, thus requiring an increased investment from Congress to ensure that we don't fall further behind in our pursuit of medical knowledge.

Colorectal Cancer Screening Awareness and Education

Colorectal cancer is the second leading cancer-related cause of death in the United States. The ASGE has made it a top priority to advocate for policies and funding that will lead to higher rates of colorectal cancer screening among men and women age 50-85. According to data from the American Cancer Society, it is estimated that nearly 146,000 people were newly diagnosed with colorectal cancer in 2009, which resulted in nearly 50,000 deaths.

Unlike other types of cancer, colorectal cancer can be prevented by the detection and removal of adenomatous polyps. Virtually all colorectal cancer develops from these pre-cancerous polyps. When colorectal cancer is diagnosed early, when it is still localized, the survival rate is significantly higher. Accordingly, colorectal cancer screening received a "Grade A" recommendation from the USPSTF. Specifically, the USPSTF recommends screening for colorectal cancer using fecal occult blood testing, sigmoidoscopy, or colonoscopy, in adults, beginning at age 50 years and continuing until age 75 years.

Experts estimate that 90 percent of colorectal cancer deaths, or 45,000 lives per year, could be eliminated if everyone age 50 and older were screened. The ASGE applauds Congress for requiring insurers, through the Patient Protection and Affordable Care Act (P.L. 111-148), to cover and waive cost sharing for preventive services that receive a grade A or B recommendation from the USPSTF. Despite this extraordinary step that will aid greatly in the fight against colorectal cancer, we know that access to screenings removes only one of the barriers to higher screening rates. Public education and awareness, especially among minority populations, are absolutely essential to reducing the number of deaths caused by colorectal cancer. This is why ASGE asks the Subcommittee to support the CDC Colorectal Cancer Control Program at \$50 million in FY 2011, an increase of \$5 million. While one-third of the funds provided to the 26 states and tribes participating in the Colorectal Cancer Control Program are dedicated for screening, the remaining funds are used for coordination, outreach, and education. Furthermore, while the change in law will improve colorectal cancer screening for those with health insurance coverage, the CDC program will be necessary to continue to fill the gap for those lacking insurance.

A February 2010 study published in the journal *Cancer* shows that the overall observed decline in colorectal cancer mortality was 26 percent for 1975-2006. Using a microsimulation model, the authors predicted that changes in risk factors accounted for 9 percent of the drop in mortality, and increased screening accounted for a 14 percent drop. Treatment contributed another 3 percent to the drop in cancer mortality. If current trends in risk factor modifications, screening, and treatment continue, a 36 percent overall decline is predicted from 2000-2020. If the projected trends can be accelerated through increased screening, then overall mortality reduction of 50 percent by 2020 is possible.⁷

By investing in medical research and prevention, Congress can help minimize the burden of digestive disease for millions of Americans. The ASGE encourages the Subcommittee to continue its support of federally funded digestive disease research and prevention by supplying federal agencies with the resources necessary to continue their work. Thank you for permitting the ASGE to share its views on this important topic.

⁷ Edwards B, Ward E, Kohler B, et al. Annual Report to the National on the Status of Cancer, 1975-2006, Featuring Colorectal Cancer Trends and Impact on Interventions (Risk Factors, Screening, and Treatment) to Reduce Future Rates. *Cancer*. 2010; Vol. 116, Issue 3.

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**Statement of the American Society for Microbiology
on the Centers for Disease Control and Prevention Appropriation for FY 2011**

The American Society for Microbiology (ASM) is pleased to submit the following testimony on the Fiscal Year (FY) 2011 appropriation for the Centers for Disease Control and Prevention (CDC). The ASM is the largest single life science organization in the world with more than 40,000 members.

The ASM is very concerned that the proposed CDC budget of \$6.6 billion for FY 2011 is 2 percent below the FY 2010 appropriation. The Administration's proposed budget is inconsistent with the need to adequately fund the agency acknowledged to be the principal federal driver in meeting our nation's goals for enhanced prevention and wellness. Focusing only on the infectious disease component of the CDC budget, the ASM notes that the Administration has proposed a \$19.6 million increase in this area. However, such a modest increase does not adequately address the growing complexity and challenges of emerging infectious diseases. These challenges have been abundantly evident over the past year with the H1N1 influenza pandemic. Furthermore, the proposed budget substantially decreases two priority program areas: the CDC's vector-borne diseases program (by \$26.7 million, which will essentially eliminate the program), and the CDC's antimicrobial resistance program (by \$6.8 million). In the FY 2011 budget, both programs are to be supported out of emerging infectious disease funds. Therefore, the proposed increase of \$19.6 million for emerging infectious diseases is insufficient to offset the \$34 million in proposed reductions for vector-borne diseases and antimicrobial resistance, resulting in a net decrease of \$15 million for emerging infectious diseases.

Eliminating funding for the vector-borne diseases program will impair CDC's collaborations with state and local partners consisting of vector-borne disease surveillance, outbreak response, the development of new diagnostics, diagnostic training and proficiency testing, as well as applied research and prevention efforts to address arboviral diseases. In the proposed budget, it is unclear what, if any, support will be available in FY 2011 for prevention and control of vector-borne pathogens. This funding reduction will essentially destroy the infrastructure developed in the past decade in response to the importation of West Nile virus in 1999 and its subsequent spread across the United States, and will leave the country vulnerable to similar importation of other vector-borne diseases.

In view of the net reduction for infectious diseases of approximately \$15 million, the ASM recommends that Congress increase the budget for emerging infectious diseases and for CDC by at least 8 to 10 percent, to restore and strengthen funding for infectious disease prevention and control and other priority public health programs.

Vector-borne Diseases. The Administration's proposed elimination of funding (-\$26.7 million) for vector-borne diseases, including West Nile virus, in its FY 2011 budget will have serious repercussions. Many emerging or reemerging infectious diseases are tied to pathogens transmitted from animals to humans, often through insect vectors. CDC programs protect public health through "one health" strategies, based on the understanding that human health is intertwined with the health of animals and the environment. The vector-borne program not only supports the West Nile virus activities, but also supports work on agents like plague, tularemia,

Lyme disease, dengue fever, and Japanese encephalitis. Lyme disease is by far the most common tickborne infection in the United States and exacts an enormous toll in health care costs and lost productivity. The US mainland is constantly threatened by the potential for establishment of dengue virus, as occurred last year in the Florida keys. Emerging public health risks like chikungunya virus in south Asia and the Indian Ocean are an ongoing concern similar to West Nile. To appropriately address vector-borne infections requires a vibrant infrastructure for detection, diagnosis, response and prevention at the national, state and local level. The proposed budget cuts will substantially dismantle the system developed in response to West Nile virus, causing much of the \$200 million investment over the last decade to disappear. The ASM urges the Administration to restore the vector-borne disease funding.

Antimicrobial Resistant Infections. The Administration's proposed budget reduces the antimicrobial resistance program by \$6.8 million. The ASM disagrees with the proposed FY 2011 decreases for crucial CDC efforts at a time when drug-resistant pathogens continue to emerge in both the community and healthcare setting. The decrease will, among other negative outcomes, substantially cut funding to states for surveillance and control programs. As a partner in the Federal Interagency Action Plan to Combat Antimicrobial Resistance, the CDC has been instrumental in tracking the grim increase in microbial pathogens resistant to antimicrobial drugs, like methicillin-resistant *Staphylococcus aureus* (MRSA). Invasive MRSA infections attack about 94,000 Americans annually, contributing to 19,000 deaths. MRSA is an increasing problem in community settings where different control strategies are necessary than in the hospital environment. A similar trend is being seen with *Clostridium difficile*, an organism once largely confined to hospital and nursing home settings but now associated with increasing severity in the community. Microbial drug resistance is driven by various factors, from pathogens' natural evolution to the growing use of antimicrobials in human and animal healthcare. One estimate suggests that between 5 and 10 percent of all hospitalized US patients acquire a drug-resistant infection, adding \$5 billion in annual healthcare costs. CDC either leads or collaborates in multiple projects against antimicrobial resistance, like the World Health Organization (WHO) effort to reduce the global spread of cephalosporin-resistant gonorrhea. Reduced funding would seriously impact the ability to mount and sustain programs to confront the problem of antimicrobial resistant pathogens.

CDC Funding: The Need for Increased Resources

Preventable diseases persist as major causes of illness and death in the United States. While life expectancy has steadily increased, influenza, pneumonia and septicemia caused by microbial pathogens remain among the top ten causes of death. The sudden emergence of pandemic H1N1 in the spring of 2009 in Mexico, California and Texas highlights the profound impact infectious diseases can have on our well being and economy. In addition to such emergent threats, other infectious diseases are on the rise. Reported cases of sexually transmitted *Chlamydia* infections have more than tripled since 1990, making it the most commonly reported infectious disease in the United States. Each year, children are absent 38 million school days due to influenza. About 43,000 Americans still develop acute hepatitis B annually, despite effective vaccines. The estimated annual cost to US hospitals of treating healthcare associated infections ranges from \$28.4 billion to \$45 billion. Foodborne illnesses continue to produce tens of millions of

infections annually. And each year, Americans visit physician offices, hospital outpatient units or emergency rooms for infectious and parasitic diseases an estimated 30 million times.

Infectious disease prevention saves lives and dollars. The CDC Office of Infectious Diseases (OID) has three programs to prevent numerous microbial diseases: the National Center for Immunization and Respiratory Diseases, the National Center for Emerging and Zoonotic Infectious Diseases and the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention. The CDC's Center for Global Health and other agency offices add expertise to the fight against disease pathogens here and abroad. In the past year, CDC personnel have contributed to the fight against H1N1 influenza and identified or confirmed the causes of disease outbreaks nationwide, like the two recent salmonellosis episodes tied to pet frogs and to black pepper. They also watched for drug-resistant tuberculosis and other communicable diseases at US ports of entry, and collaborated with local, state, federal and international partners to protect and promote good health in all 50 states, as well as nations like Haiti in response to the recent catastrophic earthquake.

Monitoring Disease, Protecting Public Health

HIV/AIDS. CDC estimates that about 1.1 million persons in the United States are living with HIV or AIDS; an estimated 21 percent do not know that they are infected. With life saving antiretroviral treatments now available, earlier diagnosis is the goal of recent CDC guidances on opt-out testing in correctional institutions and other settings and for routine screening in all health care settings for those aged 13–64 years and pregnant women, and retesting at least annually for all at high risk. In November, CDC reported that HIV incidence among intravenous drug users had declined by nearly 80 percent since the late 1980s, a positive public health outcome, yet late diagnosis of new infections persists. The FY 2011 budget increases funds for a National HIV/AIDS Strategy under development, to include renewed efforts toward HIV risk reduction.

Hepatitis. Two percent of the US population or an estimated 5.3 million are living with chronic hepatitis B (HBV) or hepatitis C (HCV), most unaware of their infection unless they later develop liver disease or cancer. Last year, a CDC study concluded that in the previous decade, failures by health care workers to follow basic infection control practices had placed more than 60,000 US patients at risk for HBV or HCV infection. In January, the Institute of Medicine called for a new, improved national strategy to prevent and control these infections. Each year an estimated 25,000 persons become infected with hepatitis A (HAV), even though rates of acute symptomatic cases have declined by 92 percent since a vaccine first became available in 1995. CDC now recommends HAV vaccine for all children at age one, since children are a major source of infection for adults who can develop more serious symptoms. CDC reported last year that vaccination among US children increased from about 26 percent in 2006 to over 47 percent in 2007, but this means that still over half of our children are needlessly at risk of a fully preventable disease like hepatitis A. They also serve as a source of infection to vulnerable adults.

Tuberculosis. In a new CDC report, preliminary statistics from the agency's National TB Surveillance System reveals that 2009 saw the largest single year decrease in US cases since data collection began in 1953. The 11,540 cases reported last year were roughly 11 percent fewer than

the previous year, with declines in both US and foreign born persons, although the TB rate among foreign born was still nearly 11 times higher. Possible explanations for the unprecedented drop, which CDC is investigating, include failure to recognize, diagnose, or report the disease due to weakening infrastructure or diversion of public health resources to the H1N1 response. This would represent a serious setback to TB disease control and elimination efforts in the United States. The emergence of tuberculosis bacteria resistant to available antimicrobial drugs has alarmed health organizations worldwide. CDC scientists identified genetic mutations associated with drug resistance in tuberculosis bacteria, which are now included in CDC laboratory testing available to state public health laboratories. CDC also is working with international partners in clinical trials of alternative drug treatments, and field trials of newer molecular-based diagnostic tests for resistance that provide results in hours to days, rather than the current weeks to months.

Foodborne/Waterborne Illness. A recent study estimates that the total economic impact of foodborne illness in the United States reaches \$152 billion annually. Last April, CDC reported that progress in foodborne illness prevention had reached a plateau, with the incidence of the most common foodborne illnesses stagnating over the previous three years after several years of decline in the late 1990s and early 2000s. Data came from the FoodNet surveillance network, a collaborative project of CDC, 10 state sites and the nation's two food safety regulatory agencies (the Food and Drug Administration and the Department of Agriculture). Of particular concern is the incidence of *Salmonella* infections, which persists at 14–16 cases per 100,000 Americans and periodically causes well-publicized disease outbreaks. This rate is stubbornly above the Healthy People 2010 target. Shortly thereafter, CDC released another report on illnesses linked to specific types of foods. Results included the following: 1) of the 1,270 outbreaks in 2006, 621 had a confirmed single cause, most often norovirus (54 percent), followed by *Salmonella* (18 percent); and 2) foods tied to the largest number of outbreak cases were poultry (21 percent), leafy vegetables (17 percent) and fruits-nuts (16 percent). Extensive CDC surveillance, done with multiple public health partners, has helped shape the current federal food safety initiative.

The ASM commends the appreciable increases in FY 2011 funding for food safety activities that will boost CDC capabilities, such as expanded outbreak surveillance and standardized investigations at the state and local level. The proposed FY 2011 budget specifically supports CDC water quality programs, including expansion of its Safe Water System and Water Safety Plan to additional countries to reduce waterborne diseases like cholera, giardiasis and cryptosporidiosis. The agency sustains multiple water quality projects, both domestically and elsewhere, ensuring safe drinking water and clean recreational waters free from microbial contamination.

Preventing Disease, Protecting Public Health

Collaborations with multiple stakeholders greatly increase the impact of CDC prevention programs. CDC grants to states and universities help build public health infrastructures against preventable illness; for instance, last fall the agency awarded over \$4 million to fund new Centers of Excellence in Public Health Informatics, and another \$5 million for biomonitoring programs in three states. In 2009, CDC joined other units of HHS in a new national initiative against healthcare-associated infections (HAI). It also announced plans last fall to distribute \$40 million in Recovery Act funding to state health departments to reduce HAIs, and is collaborating

with states to demonstrate that implementing CDC's HAI prevention guidelines can achieve major improvement. CDC estimates that every year US patients acquire 1.7 million infections while being treated in hospitals, the cause of approximately 99,000 deaths annually and an estimated \$30 billion in added healthcare costs.

Over the past year, considerable CDC resources focused on preventing H1N1 influenza, the agency's top priority in 2009. Americans have received 97 million doses of H1N1 vaccine via distribution systems established by CDC and its public health partners. Although the pandemic has been less severe than originally feared, it has still resulted in an estimated 55 million US cases since April 2009, 246,000 hospitalizations and 11,000 deaths, many in infants, children and young adults. In addition to its extensive vaccine related efforts, CDC's influenza program identified higher H1N1 death rates among American Indians and Alaska Natives, and more serious illness among pregnant women in the United States. CDC testing determined that many Americans who died from H1N1 had co-infections with the common pneumonia bacterium, *Streptococcus pneumoniae*, which likely contributed to their death. Unfortunately, vaccine preventable pneumococcal infections still kill an estimated 40,000 Americans each year. CDC officials are currently assessing the lessons learned during the 2009–2010 influenza season.

In February, CDC recommended universal use in children of an updated pneumococcal vaccine just approved by the Food and Drug Administration, which should greatly reduce *S. pneumoniae* infections and stop a leading cause of bacteremia, meningitis and pneumonia. Pneumonia kills nearly 2 million children each year, most in impoverished nations. CDC is active globally in the detection, prevention and treatment of pneumonia and other childhood infectious diseases, collaborating with WHO and dozens of nations to reduce child mortality by two thirds by 2015. WHO estimates that if all currently available vaccines against childhood diseases were widely administered, an additional two million deaths could be prevented per year.

Improving Preparedness and Response

Being prepared for the unexpected is one of CDC's primary responsibilities in protecting health and well-being. During an emergency, CDC can quickly convene expert teams and deploy both personnel and medical supplies anywhere in the world. CDC leads federal efforts to detect and contain biothreats and to ensure availability of medical countermeasures. It operates the Strategic National Stockpile, a repository of countermeasures for rapid deployment, as well as its quarantine stations at the nation's borders. It distributes grants to state and local health departments to build capacity against public health emergencies. The ASM supports additional FY 2011 funds to improve CDC's preparedness and response efforts, including the Laboratory Response Network and Select Agent Program.

In light of the significant role played by the CDC as the nation's first line of defense against a host of infectious disease threats and its leadership in national efforts to promote wellness and prevention, these efforts should not be handicapped by a funding reduction as proposed in the 2011 budget. The ASM supports an 8 to 10 percent increase in infectious disease activities to assure critical programs are not reduced or eliminated and that opportunities to prevent and control infectious diseases are not curtailed. The ASM appreciates the opportunity to comment on the FY 2011 budget for the CDC.



**AMERICAN
SOCIETY FOR
MICROBIOLOGY**

Public and Scientific Affairs Board

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**Statement of the American Society for Microbiology
on the National Institutes of Health Appropriation for FY 2011**

The American Society for Microbiology (ASM) is pleased to submit the following testimony on the Fiscal Year (FY) 2011 appropriation for the National Institutes of Health (NIH). The ASM is the largest single life science organization in the world with more than 40,000 members. The ASM mission is to enhance the science of microbiology, to gain a better understanding of life processes, and to promote the application of this knowledge for improved health and environmental well-being.

The ASM is grateful for the support of Congress for the NIH, which is the single largest source of funding for biomedical research, with an annual budget of over \$31 billion. Fiscally sustained funding for biomedical research is key to finding treatments, cures and preventions for chronic and infectious diseases. NIH supports extraordinary biomedical research successes, which are also critical to national security and a catalyst for the nation's industrial, business, and education enterprises. To ensure continued biomedical research progress and to keep pace with the cost of conducting research, we recommend that Congress provide at least an 8 percent increase for NIH, and a higher level of funding, if possible.

NIH Funding: The Need for Increased Funding for Biomedical Research

In 2009, health care costs in the United States reached \$2.5 trillion, nearly 17 percent of the gross national product and more than any other nation, yet key health outcomes need improvement. Biomedical research offers innovative individual and population based medical interventions that will improve health and productivity. In FY 2011 the NIH will support emerging technology dependent areas like computational biology and DNA sequencing, as well as basic research and trans-NIH, multidisciplinary programs. NIH has identified the following "exceptional research opportunities" to be explored in FY 2011: 1) genomics and other high-throughput technologies; 2) translational medicine to expedite the path from basic research to clinical treatments and preventives; 3) greater focus on global health; 4) use of science in support of health care reform; and 5) revitalization of medical research, including training new scientists.

In FY 2011, NIH will support research by its own 6,000 scientists and by nearly 325,000 other researchers at over 3,100 institutions, including medical schools, universities, and hospitals. About 83 percent of the FY 2011 appropriation will fund extramural research, stimulating medical innovations, local economies, and the technical workforce needed to sustain the nation's high-tech competitiveness. The Department of Health and Human Services funds 85 percent of the country's life sciences research, primarily through the 37,000 research project grants NIH will award in FY 2011.

Each dollar of NIH funding results in another two dollars in business activity and other financial benefits. Last year, analysts found that 20 percent of every NIH stimulus dollar spent under the 2009 American Recovery and Reinvestment Act (ARRA) purchased commercial products like software, instruments, and reagents, boosting technology-based industries and services.

ARRA has enabled NIH to invest \$10.4 billion over two years in NIH programs, distributed to researchers across the nation through roughly 14,000 grants to date. ARRA stimulus funds to NIH ultimately will create or retain 50,000 jobs. ARRA funding clearly has stimulated NIH research, which until recently suffered years of stagnant or declining resources.

With stimulus funds, NIH was able to support about 20 percent of grant applicants; but in FY 2011, that figure likely will drop by half, to an historically low funding rate that will impinge medical innovation in the United States. NIH received more than 20,000 proposals last year for new Challenge grants, which specifically support high risk, high return projects, but only 229 could be funded. Increased funding for NIH in FY 2011 is essential to ensure that scientists can pursue research opportunities that will lessen the human burdens of disease and disability.

NIH Funding: Foundation for Advances in Medicine

Last September, NIH and the US Army concluded their joint clinical trial in Thailand of a new AIDS vaccine, the first vaccine candidate to elicit a protective effect in humans against HIV infection. In 2009, NIH achieved advances in the global offensive against H1N1 influenza, most notably rapid development and implementation of clinical trials for various H1N1 vaccines. The three winners of the 2009 Nobel Prize in physiology or medicine had received more than \$31 million in NIH research grants, while the three Nobel winners in chemistry received over \$17 million. Their respective studies on cellular aging and on the structure and function of ribosomes have transformed medical science and will continue to do so into the future.

Worldwide, communicable diseases are responsible for 51 percent of the calculated “years of life lost” each year, according to the World Health Organization (WHO). Even in wealthy nations like the United States, preventable infectious diseases persist as leading causes of morbidity and mortality.

The National Institute of Allergy and Infectious Diseases (NIAID) sponsors a range of research activity from diseases like malaria and HIV/AIDS, to immune system disorders, biodefense, and the antibiotic resistance among pathogenic microbes to drug treatments. NIAID focuses on nearly 300 pathogens that include bacteria, viruses, parasites, fungi and prions. New therapies, vaccines, diagnostics, and other products nurtured by NIAID have benefited every American and contributed in some way to global health.

Influenza Approximately 86 million Americans have received 97 million doses of 2009 H1N1 influenza vaccine largely developed and tested with the support of NIAID. Although the H1N1 pandemic has fortunately proved to be more moderate than originally feared, it still has produced an estimated 59 million US cases since April 2009; 265,000 hospitalizations; and 12,000 deaths. Stopping H1N1 requires thorough understanding of the viral pathogen’s unique features. Ninety percent of seasonal flu deaths occur in those over 65, whereas 87 percent of reported H1N1 deaths were patients under 65. In the past year, NIAID funded numerous H1N1 studies,

including microscopic exams of respiratory tissue from fatal cases; lab experiments suggesting that H1N1 may outcompete seasonal flu virus strains and may be more communicable; a series of vaccine trials in different human subpopulations; and alternative vaccine production strategies, including tissue culture based vaccines and an early clinical trial of a candidate DNA vaccine, an experimental class of vaccine where a pathogen's genetic material is injected directly into the body.

HIV/AIDS In FY 2011, The NIH will spend nearly \$3.2 billion for research on HIV/AIDS, which remains one of the most intractable health challenges faced by the world. An estimated 33 million people are living with HIV worldwide, and another 2 million have died. Each year, there are 56,300 new HIV infections in the United States; of the estimated 1.1 million Americans living with HIV, 21 percent are unaware of their infection. The NIAID's Vaccine Research Center investigates multiple approaches to new vaccine development, like how neutralizing antibodies develop during natural HIV infection, which could point to an effective vaccine. NIAID also supports other prevention strategies, such as using antiretroviral drugs to stop mother to child HIV transmission (an estimated 430,000 children became infected in 2008, mostly through birth or breastfeeding from an HIV infected mother). In 2009, NIAID outlined its "test and treat" prevention agenda, based on a WHO mathematical model predicting that universal, voluntary, annual HIV testing and immediate treatment for those who test positive could radically reduce HIV incidence within a decade, and potentially end the pandemic within 50 years.

Global Health Infectious diseases can quickly spread through the world's populations and across national borders. Global health research at NIAID informs science based public health policies worldwide, and the institute participates in several global partnerships with entities like WHO and UNICEF. It also has interagency agreements with USAID, CDC, NASA, and the State Department to combat diseases that migrate from country to country. With its scientific expertise in major global diseases, NIAID will be a vital contributor to the Administration's new Global Health Initiative (GHI) designed to reform and coordinate US support for international health. NIAID has established programs tied to four of the six GHI focus areas, that is, HIV/AIDS, tuberculosis, malaria, and neglected tropical diseases (also, health systems and health workforce; maternal, newborn, and child health).

Malaria threatens an estimated 3.3 billion people, nearly half of the world's population. Each year, this age-old disease causes about 250 million clinical cases and nearly 1 million deaths, most of those deaths in and children under 5 years and pregnant women. At least four species of the causative *Plasmodium* protozoa are transmitted through bites from dozens of *Anopheles* mosquito species, all of which can develop resistance to known pesticides and antimalarial drugs and a fifth human malaria parasite was recently discovered in Asia. The complex parasite vector human host cycle ranks malaria among medicine's grand challenges. NIAID funds basic and applied research to develop tools and strategies for the treatment, prevention, and control of this disease.

One-third of the world's population is infected with the pathogen *Mycobacterium tuberculosis*. There are 9.4 million new tuberculosis cases annually and 1.8 million deaths, making TB the leading cause of global mortality after HIV/AIDS. Public health efforts against TB are often

outmoded, the mostly commonly used diagnostics were developed a century ago, there have been no new drugs introduced for decades, and the last new vaccine was produced 40 years ago. Therapy is difficult at best, and the emergence of drug-resistant strains has greatly complicated treatment. TB cases classified as “extensively drug resistant” (XDR) now occur in nearly 60 nations, with mortality rates exceeding 95 percent in some areas. NIAID funding supports research to discover updated diagnostics, therapeutics, and vaccines.

The so called “neglected tropical diseases” (NTDs) like leishmaniasis, sleeping sickness, and Chagas disease cumulatively infect over one billion people and kill 534,000 per year. WHO categorizes 14 diseases as NTDs important to global health, serious illnesses that most often affect impoverished countries. Many are often fatal, usually ignored by control and treatment programs, and associated with poor surveillance tools and systems. NIAID already conducts research on selected NTDs, including ARRA funded projects awarded last year that include the following: investigating the role of immunological markers like T-cells in the pathology of Chagas disease in Bolivia; conducting a prevalence study of toxocariasis and cysticercosis in HIV patients; screening Panamanian cyanobacteria, fungi, and bacteria for potential new drugs against NTDs; and designing a detailed spatial map of the onchocerciasis endemic areas in West Africa using satellite and epidemiological data. NIH also funds research creating models of human health impacts of climate change, including potential shifts in cholera transmission.

NIH Funding: Defense Against Emerging Infectious Diseases

The proposed FY 2011 budget increases funding for NIAID’s activities emerging infectious diseases. These diseases might migrate or evolve naturally, perhaps developing resistance to standard drug treatments, or their pathogens might be deliberately dispersed as agents of bioterrorism.

NIAID funding has created countermeasures against anthrax, botulinum toxin, and smallpox. It also supports research on diseases less well-known in the United States, such as dengue fever, prion diseases like chronic wasting disease, and chikungunya fever. Scientists at NIAID recently reported success with an experimental vaccine against chikungunya virus, a mosquito borne pathogen that infects millions in Africa and Asia and causes painful joint swelling, for which there currently is no specific vaccine or treatment. Last year, researchers identified cell components in mosquitoes and humans that dengue viruses use to multiply inside their hosts, suggesting new drug targets. At present, there are no dengue-specific drugs to treat an illness that sickens 50–100 million people each year. In March, NIAID scientists reported a new form of a prion disease in laboratory mice that causes brain damage resembling that caused by a type of Alzheimer’s disease in humans.

In recent years, alarmed public health officials have devoted increasing resources toward mitigating the social and economic impacts of antimicrobial resistance. NIAID supports multiple projects devoted to the biological aspects of this problematic phenomenon. Drug resistant pathogens of greatest concern include methicillin resistant *Staphylococcus aureus* (MRSA), vancomycin-resistant enterococci (VRE), and the microbial causes of malaria, HIV/AIDS, influenza, tuberculosis, streptococcal pneumonia, and various foodborne illnesses. Many resistant infections develop in health care settings. Each year, about two million people develop infections in US hospitals, with 90,000 deaths. About 70 percent of those infections are linked to

pathogens resistant to at least one drug. Data now indicate that the problem outside health care settings is greater than originally believed. In FY 2011, NIAID will fund a new initiative, Development of Therapeutic Products for Biodefense, with particular emphasis on broad spectrum products or those addressing the growing dilemma of antimicrobial resistance.

NIH Funding: Moving Forward in Biomedical Research

Federal funding for NIH centers and institutes underwrites some of the world's most creative, most promising biomedical research. Discoveries through NIAID and NIGMS programs have fostered breakthrough tools and methods vital to sectors of the US medical enterprise, like biotechnology. Research strategies at NIH must take advantage of cutting edge technologies and modern scientific disciplines like genomics and bioinformatics. NIAID research partnerships will develop next-generation biodefense diagnostics, like those using nanotechnology-based microfluidic platforms, *in vivo* imaging methods, or other emerging technologies. NIH supported scientists are finding novel approaches to vaccines and therapeutics, like the bioengineered use of tobacco plants to make a nasal vaccine against norovirus and a treatment for West Nile virus infection

By supporting high risk/high return projects, NIGMS lays the foundation for future advances in disease diagnosis, treatment, and prevention. It promotes large-scale initiatives to solve complex problems through collaborative research. An example is the NIGMS pharmacogenetics research program, which integrates laboratory science and databases linking genes, medicines, and diseases. In December, NIGMS announced five new projects in its pharmacogenomics collaboration with Japan's Center of Genomic Medicine; one will examine why antiretrovirals used to treat HIV are not effective in some people.

FY 2011 funding for NIH will support the necessary acquisition of the "forward technologies" important to intramural and extramural investigators. Examples include geographic information systems for disease surveillance, and genomics tools like cloud computing, DNA sequencing software, and single-cell technologies able to assess activities within an individual cell. NIH funding also invests in the future by building the workforce needed to sustain innovation. Each year, NIH also provides grants for STEM education across the United States, and supports pre- and postdoctoral scientists at the NIH campus or with fellowships elsewhere. NIGMS alone supports approximately 50 percent of PhD training positions at NIH.

Conclusion

NIH projects contribute to improving public health, local economies, and science education. NIH plays a key role in accelerating transformation of basic science into clinical tools that save lives. The ASM recommends that Congress approve at least an 8 percent increase for the National Institutes of Health.

**Statement of the American Society for Nutrition (ASN)
Submitted to the House Appropriations Subcommittee on Labor, Health and Human
Services, Education and Related Agencies on Fiscal Year 2011 Funding
for the National Institutes of Health and the National Center for Health Statistics**

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The American Society for Nutrition (ASN) appreciates this opportunity to submit testimony regarding fiscal year (FY) 2011 appropriations for the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS). ASN is the professional scientific society dedicated to bringing together the world's top researchers, clinical nutritionists and industry to advance our knowledge and application of nutrition to promote human and animal health. Our focus ranges from the most critical details of research to very broad societal applications. **ASN respectfully requests \$37 billion for NIH, and we request \$162 million for NCHS in fiscal year (FY) 2011.**

Basic and applied research on nutrition, nutrient composition, the relationship between nutrition and chronic disease and nutrition monitoring are critical to the health of all Americans and the U.S. economy. Awareness of the growing epidemic of obesity and the contribution of chronic illness to burgeoning health care costs has highlighted the need for improved information on dietary components, dietary intake, strategies for dietary change and nutritional therapies. Preventable chronic diseases related to diet and physical activity cost the economy over \$117 billion annually, and this cost is predicted to rise to \$1.7 trillion in the next ten years. It is for this reason that we urge you to consider these recommended funding levels for two agencies under the Department of Health and Human Services that have profound effects on nutrition research, nutrition monitoring, and the health of all Americans—the National Institutes of Health and the National Center for Health Statistics.

National Institutes of Health

The National Institutes of Health (NIH) is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 90 percent (over \$1.4 billion) of federally-funded basic and clinical nutrition research. Nutrition research, which makes up about four percent of the NIH budget, is truly a trans-NIH endeavor, being conducted and funded across multiple Institutes and Centers. Some of the most promising nutrition-related research discoveries have been made possible by NIH support.

In order to fulfill the extraordinary promise of biomedical research, including nutrition research, **ASN recommends an FY 2011 funding level of \$37 billion for the agency.**

Over the past 50 years, NIH and its grantees have played a major role in the explosion of knowledge that has transformed our understanding of human health, and how to prevent and treat human disease. Because of the unprecedented number of breakthroughs and discoveries made possible by NIH funding, scientists are helping Americans to live longer, healthier and more

productive lives. Many of these discoveries are nutrition-related and have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and age-related macular degeneration.

During the next 25 years, the number of Americans with chronic disease is expected to reach 46 million, and the number of Americans over age 65 is expected to be the largest in our nation's history. Sustained support for basic and clinical research is required if we are to confront successfully the health care challenges associated with an older, and potentially sicker, population.

For several years in a row the NIH budget failed to keep up with inflation and subsequently, the percentage of dollars funding nutrition-focused projects declined. Thanks to Congress' inclusion of nearly \$10 billion for NIH in H.R. 1, the American Recovery and Reinvestment Act, the scientific enterprise has been revitalized and additional biomedical research projects have been supported. ASN was pleased to see that ARRA provided over \$300 million for nutrition research projects over two years. These projects also are, in addition to generating new findings to improve human health and nutrition, providing jobs and generating commercial activity throughout the broader community. It is imperative that we continue our commitment to biomedical research and to fulfill the hope of the American people by making the NIH a national priority. Otherwise, we risk losing our nation's dominance in biomedical research.

The research engine needs predictable, sustained investment in science to maximize our return on investment. Recent experience has demonstrated how cyclical periods of rapid funding growth followed by periods of stagnation is disruptive to the discovery process, can lead to fewer students choosing careers in research, impedes long range projects and ultimately slows progress. NIH needs sustainable and predictable budget growth to achieve the full promise of medical research to improve the health and longevity of all Americans.

CDC National Center for Health Statistics

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention (CDC), is the nation's principal health statistics agency. The NCHS provides critical data on all aspects of our health care system, and it is responsible for monitoring the nation's health and nutrition status. Nutrition and health data, largely collected through the National Health and Nutrition Examination Survey (NHANES), is essential for tracking the health and well being of the American population, and it is especially important for observing health trends in our nation's children. Knowing both what Americans eat and how their diets directly affect their health provides valuable information to guide policies on food safety, food labeling, food assistance, military rations and dietary guidance. Not surprisingly, NHANES serves as a gold standard for nutrition and health data collection around the world.

For several years, flat and decreased funding levels threatened the collection of this important information, most notably vital statistics from the NHANES. Beginning in FY 2009, Congress made a renewed commitment to this agency by appropriating an additional \$11 million to the agency—for nearly \$125 million total—in FY 2009 and a \$14 million boost in FY 2010. Actions in FY 2009 halted what would have been the beginning of drastic cuts to the agency's premier health surveys—NHANES and the National Health Information Survey—that were slated to occur should the agency not receive additional funds. Last year's continued support enabled the agency to rebuild after years of underinvestment. ASN appreciates very much the

leadership this subcommittee has shown in securing steady and sustained funding increases for NCHS over the past three fiscal years.

To continue support for the agency and its important mission, **ASN supports the President's FY 2011 budget request of \$162 million for the agency.**

The obesity epidemic is a case in point that demonstrates the value of the work done by NCHS. It is because of NHANES that our nation became aware of this growing public health problem, and as obesity rates have increased to 31 percent of American adults (which we know because of continued monitoring), so too have rates of heart disease, diabetes and certain cancers. It is only through continued support of this program that the public health community will be able to stem the tide against obesity. Continuous collection of this data will allow us to determine not only if we have made progress against this public health threat, but also if public health dollars have been targeted appropriately. A recent report from the Institute of Medicine recognized the importance of NHANES and called for the enhancement of current surveillance systems to monitor relevant outcomes and trends with respect to childhood obesity.¹

Now that health care reform has been signed into law, collecting health statistics is of even greater importance. Providing an additional \$23 million in FY 2011 continues the progress on a path that can mitigate previous years of flat-funding and ensure we have a 21st century health statistics system in the U.S.

ASN thanks your Committee for its support of the NIH and NCHS in previous years. If we can provide any additional information, please contact Mary Lee Watts, ASN Director of Science and Public Affairs, at (301) 634-7112 or mwatts@nutrition.org.

Sincerely,



Robert M. Russell, MD
President, American Society for Nutrition

¹ Institute of Medicine. *Progress in Preventing Childhood Obesity* Washington, DC: National Academies Press, 2006.

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**Written testimony of the American Society for Pharmacology and Experimental Therapeutics to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education & Related Agencies
Fiscal Year 2011
Appropriations for the National Institutes of Health**

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health (NIH) FY 2011 budget. ASPET is a 4,900 member scientific society whose members conduct basic and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases as well as increasing our knowledge regarding how therapeutics affects humans. For FY 2011, ASPET supports a \$37 billion NIH budget. This FY 2011 budget recommendation for NIH is consistent with that of the Federation of American Societies for Experimental Biology (FASEB).

ASPET members recognize the trust and support that Congress displayed in 2009 and 2010 with the \$10.4 billion provided to the NIH in the American Recovery and Reinvestment Act (ARRA). This was a visionary attempt by Congress to stimulate the economy by restoring their historic financial support of the NIH. Prior to ARRA funding, the NIH research portfolio failed to keep pace with the inflation rate and this country's leadership in biomedical research was in danger. Since the completion of a bipartisan plan to double the NIH budget that ended in 2003, the NIH budget had been sliding backwards. ARRA funding has helped to restore this funding deficit. But ARRA's promise will only be met with continued robust and sustainable funding to take advantage of the many research discoveries and opportunities resulting from this stimulus that will lead to healthier lives for all through new forms of therapies, technologies, drugs and research directions. There is tremendous scientific capacity in our nation that is not appropriately supported. For example, as a result of ARRA funding, NIH received over 20,000 Challenge Grants applications for less than 800 awards. Adequate and sustained funding in FY 2011 will represent a first step in tapping into this unmet potential.

A FY 2011 NIH budget of \$37 billion would help to sustain the existing NIH momentum gained through ARRA funding. Scientific discovery takes time and cannot be effective when pursued episodically. As recent experience has shown from the post-doubling experience, "boom and bust" cycles of rapid funding followed by significant periods of stagnation or retraction in the NIH budget diminish scientific progress. A \$37 billion FY 2011 NIH budget will help the agency manage its research portfolio effectively without disrupting the continuity of existing grants to researchers throughout the country. The NIH, and the entire scientific enterprise, cannot rationally manage boom or bust funding cycles. Only through steady, sustainable and predictable funding increases

can NIH continue to fund the highest quality biomedical research to help improve the health of all Americans and continue to make significant economic impact in many communities across the country. In FY 2011, failure to capitalize on the 2010 ARRA investments will mean that NIH will have to dismantle newly built research capacity and terminate important research projects after the ARRA funds have been spent. This would have serious consequences for future scientific discovery as well as for many local economies dependent upon the research enterprise. If NIH cannot sustain its recent investments from the ARRA, a rapid decline of funding will further disrupt the scientific careers of many promising young and early career scientists who see little hope of rewarding careers in biomedical research. It is critical to avoid a boom and bust cycle for NIH funding. A FY 2011 NIH budget of \$37 billion will help achieve the full promise of biomedical research.

NIH Improves Human Health and is an Economic Engine

Inadequate funding for NIH will mean a loss of scientific opportunities to discover new therapeutic targets, and fewer discoveries that produce spin-off companies that employ individuals in districts around the country. A \$37 billion FY 2011 NIH budget would provide the various institutes that make up the NIH with an opportunity to fund more high quality and innovative research, and provide the resources and incentives that will encourage more young scientists to commit to careers supporting continuing improvements in public health. This investment also will directly support jobs for US citizens and residents and will continue to stimulate the economy. Failure to capitalize on ARRA funding in FY 2011 will also send a wrong signal to the best and brightest of our students who will not be able to pursue a career in biomedical research. Failing to address the NIH scientific and infrastructure needs post-ARRA in 2011 and beyond will mean a significant reduction in research grants, jobs lost and the resulting phasing-out of research programs.

Many important drugs have been developed as a direct result of the basic knowledge gained from federally funded research, such as new therapies for breast cancer, the prevention of kidney transplant rejection, improved treatments for glaucoma, new drugs for depression, and the cholesterol lowering drugs known as statins that help prevent 125,000 deaths from heart attack each year. In just over a decade, AIDS related deaths have fallen by more than 73% with the development of antiretroviral therapies, and the five-year survival rate for childhood cancers rose to almost 80% from under 60% in the 1970s. Heart disease deaths are down 63% and deaths from strokes are down 70% since the 1970s. NIH studies have indicated that adopting intensive lifestyle changes delayed onset of type-2 diabetes by 58%, and that progesterone therapy can reduce premature births by 30% in women at risk. The National Research Council reported that of the 21 drugs with the highest therapeutic impact, only five were developed without input from the public sector.

Historically, our past investment in basic biological research has led to innovative medicines that have virtually eliminated diphtheria, whooping cough, measles and polio in the U.S. Eight out of ten children now survive leukemia. Death rates from heart disease and stroke have been reduced by half in the past 30 years. Molecularly targeted drugs such as Gleevec™ to treat adult leukemia do not harm normal tissue and dramatically improve survival rates. NIH research has developed a

class of drugs that slow the progression of symptoms of Alzheimer's disease. The robust past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenetics and a reduction in adverse drug reactions that currently represent a major worldwide health concern.

But unless NIH can maintain an adequate funding stream, scientific opportunities will be delayed, lost, or forfeited to biomedical research opportunities in other countries and the human and economic cost will continue to impact all of us.

Scientific inquiry leads to better medicine and there remain many challenges and opportunities that need to be addressed. Two issues specific to ASPET highlight the need for appropriate NIH funding levels.

- The need to increase support for training and research in integrative/whole organ science. This will help to develop skilled scientists trained to understand how drugs act in whole animals, including human beings. Support for training and research in integrative whole organ sciences has been affirmed in the FY 2002 U.S. Senate Labor/Health and Human Services & Related Agencies Appropriations Report (107-84). The Senate report supports ASPET recommendation that "Increased support for research and training in whole systems pharmacology, physiology, toxicology, and other integrative biological systems that help to define the effects of therapy on disease and the overall function of the human body." These principles and recommendations are also affirmed in the FASEB Annual Consensus Conference Report on Federal Funding for Biomedical and Related Life Sciences Research for FY 2002.
- The need to meet public health concerns over growing consumer use of botanical therapies and dietary supplements. These products have unsubstantiated scientific efficacy and may adversely impact the treatment of chronic diseases, create dangerous interactions with prescription drugs, and may cause serious side effects including death among some users. Through the NIH, research into the safety and efficacy of botanical products can be conducted in a rigorous and high quality manner. Sound pharmacological studies will help determine the value of botanical preparations and the potential for their interactions with prescription drugs as well as chronic disease processes. This research will allow the FDA to review the available pharmacology and assess valid evidence-based findings to form a valid scientific foundation for regulating these products.

Conclusion

ASPET has full appreciation for the many compelling priorities facing the Subcommittee. We are keenly aware of the critical fiscal problems our nation confronts. But NIH and the biomedical research enterprise face a critical moment and the agency's contribution to the economic and physical well being of American's health should make it one of the nation's top priorities. ARRA provided a brief, but critical opportunity to help with this success. With enhanced and sustained funding, NIH has the potential to meet many of the more promising scientific opportunities that

currently challenge medicine. ARRA helped to reverse the zero growth trends in NIH funding of the last half decade, but is only a temporary solution if NIH cannot continue to grow. In order to help sustain scientific progress it is critical that NIH receive a FY 2011 budget of \$37 billion. A \$37 billion FY 2011 NIH budget will permit the agency to make greater strides to prevent, diagnose and treat disease, improving the health of our nation, restoring the NIH to its role as a national treasure that attracts and retains the best and brightest to biomedical research, and providing hope to millions of individuals afflicted with illness and disease.

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Written testimony prepared for:
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies,
United States House of Representatives Committee on Appropriations

Regarding funding for the National Institutes of Health for FY 2011

April 16, 2010

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing more than 28,000 physicians and other professionals who treat people with cancer, appreciates this opportunity to express our views on funding for the National Institutes of Health for FY 2011. ASCO's members set the standard for cancer patient care worldwide and lead the way in carrying out clinical research aimed at improving the screening, prevention, diagnosis and treatment of cancer. ASCO's efforts are also directed toward advocating for policies that provide access to high-quality care for all patients with cancer and supporting the clinical and translational research in the area of oncology that is critical to improving the lives of our citizens.

ASCO thanks the committee for its continued investment in cancer research through the annual appropriations process, as well as through the American Recovery and Reinvestment Act (ARRA). The years of investment in cancer research are paying off in the most important ways – deaths rates are decreasing, survival rates are increasing, and treatments have fewer side-effects. Researchers are discovering that not only is cancer made up of hundreds of diseases, but these diseases have numerous subtypes that can be treated with targeted therapies. This translates to progress in treatments, as well as the need for exponentially more research. Without sustained and predictable increases in funding for the National Institutes of Health (NIH) and the National Cancer Institute (NCI), the progress that has been made will be significantly delayed. On behalf of the cancer community, we wish to highlight that we are very grateful for the support of the Administration and Congress, which resulted in NIH receiving an inflationary increase in FY 2010. However, between 2004 and 2008, NIH actually lost over 13% of the purchasing power it had in 2003, the final year of the NIH budget doubling period.

In addition to providing important economic stimulus to local communities throughout the United States provided through funding for research, the ARRA funding for research helped restore this significant decline in NIH purchasing power. With the ARRA funding, Congress temporarily reinstated the impact and spirit of doubling the NIH budget. Progress in fighting cancer would be faster, more efficient, and more sustainable if funding were equally steady and sustainable.

Appropriations for FY 2011 for the National Institutes of Health

ASCO is joining with the biomedical research community in respectfully requesting the Subcommittee appropriate \$35 billion to NIH for FY 2011. This request would maintain the total funding levels from FY 2010 (including an annualized portion of the ARRA funds for research, which is 50 percent of the total ARRA funds for research,) and allow us to sustain the pace of research made possible with ARRA. By adding an annualized portion of the research dollars provided by ARRA to the base budget of NIH, important advancements will continue to be made.

Research is a long-term process and allowing the important work begun with ARRA funds will ensure faster progress in cancer research. Progress that has meaning and important positive impacts in patients' lives will continue to be made – it is a question of how quickly progress will be made going forward and whether researchers in the United States will continue to play a leadership role in pursuing these advancements.

ASCO is also respectfully requesting that the Subcommittee dedicate itself to a sustained, multi-year commitment to research funding. Meaningful progress cannot be made if NIH funding does not keep pace with the annual increase in the cost of conducting biomedical research. Unpredictable increases and decreases in NIH funding not only make it difficult for NIH to make commitments to multi-year projects, but also serve to discourage the best and brightest researchers to pursue careers in medical research. Sustained and predictable funding is key to a prosperous and vigorous biomedical research enterprise.

Benefits of the American Recovery and Reinvestment Act

ARRA has given biomedical research a much needed boost in funding, but those funds are set to expire on September 30, 2010. ARRA has made it possible to enhance important research projects at NIH and the NCI, such as accelerating the identification of genomic alterations in tumor types in The Cancer Genome Atlas. This project is mapping cancer genes and will lead to increased understanding of how to target new treatments to halt the development and spread of cancer. Other uses of ARRA funds at NCI include the Accelerating Clinical Trials of Novel Oncologic Pathways (ACTNOW), the Cancer Human Biobank, and grants to Cancer Centers all across the country to promote personalized cancer care and drug development. These efforts are the beginning of a long-term process to translate discoveries into new treatments for cancer patients. Preservation of ARRA funds in the base NIH budget is necessary to translate these important discoveries into meaningful improvements in care for cancer patients.

Funding cancer research also benefits local communities. According to a Families USA report, for every dollar in grants given by NIH, the economic benefit to the local community is, on average nationally, \$2.21 in economic stimulus by way of new business activity, jobs and wages.

Clinical Trials and Translational Research

In the area of oncology, clinical trials play a significant role in the day-to-day treatment options that should be available to patients, in large part because clinical trials often provide the best hope for successful treatment for cancer patients. NIH and NCI are leading the way by funding some very important data-driven translational research and clinical trials, bringing new,

innovative therapies from research laboratories into clinics and hospitals to offer our patients targeted, personalized care. Clinical trials are absolutely critical to identify better, more cost effective care and longer lives for cancer patients. Translational research and clinical trials have changed the standard of care in many cancers.

Clinical trials funded by NIH and NCI examine important questions that are not being investigated elsewhere, generate practice-changing science, and often recruit difficult to reach sub-populations. Unfortunately, these trials are at risk, due to concerns about inadequate funding, the pace of the trials and accrual rates. Clinical trials are increasingly being conducted overseas, due to the costs and regulatory complexities of conducting trials in the United States. This denies your constituents the opportunity to participate, either as a physician conducting research or as a patient enrolling in a clinical trial. Congress must demonstrate a continued commitment to ensure biomedical research is federally funded. NIH research advances have transformed the way cancer is prevented, detected and treated, and cancer has become a much more survivable disease as a result.

Federal funding has led to advances in screening that significantly contributed to the decline in cancer death rates. Federally funded clinical trials have also contributed directly to most patients having meaningful access to recommended chemotherapy regimens within their communities, often with far fewer side effects than in the past. Today, as a direct result of the investment in biomedical research (i.e., clinical trials and translational research), we are implementing changes that are improving cancer care for our patients.

Because of these advances and the incredible scientific opportunities facing us, ASCO urges the NIH and NCI to focus more of its resources in the area of clinical trials and translational research. Specifically, ASCO would also like to see an increase in the NCI per-case reimbursement for physicians who enroll patients on federally funded clinical trials. Studies conducted by ASCO and C-Change indicate that the current payment rate accounts for only half of the actual extra costs imposed on health care providers to enroll and participate within NCI-funded clinical trials. An ASCO survey of clinical trial sites in August 2009 revealed that a significant portion of sites are considering limits to their participation in federally funded research – in large part due to the inadequate funding provided. The funding NCI provides to sites that participate in their trials should be increased to account for actual research costs and keep pace with the growing costs of collecting and maintaining data and hiring skilled staff to oversee the research.

ASCO again thanks the Subcommittee for its continued dedication to Americans facing cancer through support of the important work accomplished under the guidance of the National Institutes of Health and the National Cancer Institute. We look forward to working with all members of the Subcommittee to advance cancer research.



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**Position Statement on the FY 2011 Budget Request for the
National Institutes of Health (NIH) Submitted by the
NIH Task Force of the Bioengineering Division**

April 16, 2010

The NIH Task Force (“Task Force”) of the Inter Sector Committee on Federal Research and Development (ISCFRD) of ASME is pleased to provide comments on the bioengineering-related programs contained within the National Institutes of Health (NIH) Fiscal Year (FY) 2011 budget request. The Task Force is focused on the application of mechanical engineering knowledge, skills, and principles for the conception, design, development, analysis, and operation of biomechanical systems.

The Importance of Bioengineering

Bioengineering is an interdisciplinary field that applies physical, chemical, and mathematical sciences, and engineering principles to the study of biology, medicine, behavior, and health. It advances knowledge from the molecular to the organ levels, and develops new and novel biologics, materials processes, implants, devices, and informatics approaches for the prevention, diagnosis, and treatment of disease, for patient rehabilitation, and for improving health. Bioengineers have employed mechanical engineering principles in the development of many life-saving and life-improving technologies, such as the artificial heart, prosthetic joints, diagnostics, and numerous rehabilitation technologies.

Background

The NIH is the world's largest organization dedicated to improving health through medical science. During the last 50 years, NIH has played a leading role in the major breakthroughs that have increased average life expectancy by 15 to 20 years.

The NIH is comprised of different Institutes and Centers that support a wide spectrum of research activities including basic research, disease and treatment-related studies, and epidemiological analyses. The mission of individual Institutes and Centers varies from either study of a particular organ (e.g. heart, kidney, eye), a given disease (e.g. cancer, infectious diseases, mental illness), a stage of life (e.g. childhood, old age), or finally it may encompass crosscutting needs (e.g., sequencing of the human genome and the National Institute of Biomedical Imaging and Bioengineering (NIBIB).

The total fiscal year (FY) 2011 NIH budget request is \$32.2 billion, or 3.2 percent above the \$31.2 billion FY10 appropriated amount. The Task Force recognizes that this proposed increase is significant given the Administration’s commitment to reducing the federal deficit. However, the Task Force notes that the Administration’s 3.2 percent increase to the overall NIH budget is less than the up to 3.8% projected increase in

research costs due to inflation – as predicted by the Biomedical Research and Development Price Index (BRDPI) – and as a consequence actually results in an effective decrease in funding for the NIH compared to FY 2010. The Task Force therefore recommends out-year budget increases well beyond BRDPI inflation rates to compensate for this flat level of funding.

The Task Force further notes that NIH received \$10.4 billion as part of the American Recovery and Reinvestment Act (ARRA) of 2009 (P.L. 111-5), an important influx for several key divisions of NIH over the FY09 and FY10 funding cycles, particularly the NIBIB, which received \$78 million - less than 1% of the \$10.4 billion ARRA budget assigned to the NIH for the FY09 and FY10 funding cycles. NIBIB has already exhausted approximately 95% of this budget, leaving little ARRA funding to leverage through the FY10 budget cycle and underscore the need for more robust investment in bioengineering at NIBIB. While this one-time influx of funding for health research and infrastructure was justified, the Task Force notes that the unstable nature of such funding inhibits the potential impact on the economy and should not be viewed as a viable substitute for steady and consistent support from Congress for these critical national research priorities.

Overall research and development activities are expected to account for 97.4 percent of the total FY 2011 NIH budget, or \$31.4 billion. With this, the Administration estimates 9,052 research project grants (RPGs) will be supported, 199 less than FY10, essentially flat year-on-year. Of the Administration's priority programs this year, the Task Force commends the recommended \$382 million in support for the National Nanotechnology Initiative, a 6.0 percent or \$22 million increase over FY10.

NIBIB Research Funding

The Administration's FY 2011 budget requests \$325.93 million for the NIBIB, an increase of \$9.47 million or 3.0 percent from the FY10 appropriated amount. This increase is less than the 3.8% projected increase in research costs due to inflation (predicted by the BRDPI index) and, as a consequence, actually results in an effective decrease in funding for NIBIB compared to FY 2010. The mission of the NIBIB is to seek to improve human health by leading the development and application of emerging and breakthrough technologies based on a merging of the biological, physical, and engineering sciences.

The budget for NIBIB Research Grants would increase by \$6.1 million to \$268.8 million, a 2.4 percent increase from FY10. Funding for intramural research would increase 3.6 percent to \$11.5 million from \$11 million in FY10. NIBIB's Research Management and Support request is \$17.7 million, a 5.4 percent increase or \$0.84 million over FY10.

NIBIB funds the Applied Science and Technology (AST) program, which supports the development and application of innovative technologies, methods, products, and devices for research and clinical application that transform the practice of medicine. The FY 2011 request for AST is \$176.8 million, a \$5.2 million increase or 3.0 percent from FY 2010.

Additionally, NIBIB funds the Discover Science and Technology (DST) program, which is focused on the discovery of innovative biomedical engineering and imaging principles

for the benefit of public health. The FY11 request for DST is \$95.1 million, a \$2.2 million or 2.4 percent increase from FY10.

The Technological Competitiveness-Bridging the Sciences program, which funds interdisciplinary approaches to research, would receive \$24.9 million in FY 2011, a \$0.9 million increase or 3.6 percent over the FY 2010 enacted level.

Task Force Recommendations

- The Task Force is concerned that the United States faces rapidly growing challenges from our counterparts in the European Union and Asia with regards to bioengineering advancements. While total health-related US research and development investments have expanded significantly over the last decade, investment in bioengineering at NIBIB have remained relatively flat over the last several years. In fact, the FY2011 budget actually represents a small reduction in funding when the FY2003 NIBIB appropriation of \$280 million is adjusted for inflation (\$329 million in 2010 dollars).

The Task Force wishes to emphasize that, in many instances, bioengineering-based solutions to health care problems can result in improved health outcomes and reductions in health care costs -- a fundamental tenet of the President's National Innovation Strategy. For example, coronary stent implantation procedures cost approximately twenty thousand dollars, compared to bypass graft surgery at double the cost. Stenting involves materials science (metals and polymers), mechanical design, computational mechanical modeling, imaging technologies, etc. that bioengineers work to develop. Not only is the procedure less costly, but the patient can return to normal function within a few days rather than months to recover from bypass surgery, greatly reducing other costs to the economy. Therefore, we strongly urge Congress to consider increased funding for bioengineering within the NIBIB and across NIH, and work to strengthen these investments in the long run to reduce US health care costs and support continued US leadership in bioengineering.

- The NIBIB must obtain sustained funding increases, both to accelerate medical advancements as our nation's population ages, and to mirror the growth taking place in the bioengineering field. The Task Force believes that the Administration's budget request for FY 2010 is not aligned with the challenges posed by this objective; a 3.0% budget increase will not keep up with current inflationary increases for biomedical research, eroding the United States' ability to lay the groundwork for the medical advancements of tomorrow.
- While the Task Force supports federal proposals that seek to double federal research and development in the physical sciences over the next decade, we believe that strong federal support for bioengineering and the life sciences is especially essential to the health and competitiveness of the United States. The supplemental funding that NIH received as part of ARRA and the budget request by the Administration does not completely erase the past several years of disappointing budgets. Congress and the Administration should work to develop a specific plan, beyond President Obama's call for 'innovations in health care technology' in his 'Strategy for American Innovation', to focus on specific and

attainable medical and biomedical research priorities which will reduce the costs of health care and improve health care outcomes. Further, Congress and the Administration should include in this strategy new mechanisms for partnerships between NSF and the NIH to promote bioengineering research and education. The Task Force feels these initiatives are necessary to build capacity in the US bioengineering workforce and improve the competitiveness of the US bioengineering research community.

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American Society of Plant Biologists

Official Written Testimony for Fiscal Year 2011 Budget
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
United States House of Representatives
Washington, D.C.

Submitted by
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&
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April 8, 2010

On behalf of the American Society of Plant Biologists (ASPB) we would like to thank the Subcommittee for its extraordinary support of the National Institutes of Health (NIH) and ask that the Subcommittee Members encourage increased funding for plant biology research, which has contributed in innumerable ways to improving the lives of people throughout the world.

The American Society of Plant Biologists is an organization of more than 5,000 professional plant biologists, educators, graduate students, and postdoctoral scientists. A strong voice for the global plant science community, our mission -- which is achieved through engagement in the research, education, and public policy realms -- is to promote the growth and development of plant biology and plant biologists and to foster and communicate research in plant biology. The Society publishes the highly cited and respected journals *Plant Physiology* and *The Plant Cell*, and it has produced and supported a range of materials intended to demonstrate fundamental biological principles that can be easily and inexpensively taught in school and university classrooms by using plants.

Plant Biology Research and America's Future

Plants are vital to our very existence. They harvest sunlight, converting it to chemical energy for food and feed; they take up carbon dioxide and produce oxygen; and they are almost always the primary producers in the Earth's ecosystems. Plants and plant-based products directly or indirectly provide our food, our shelter, and our clothing.

Plant biology research is making many fundamental contributions in vital areas including health and nutrition, energy, and climate change. For example, because plants are the ultimate source of

both human nutrition and nutrition for domestic animals, plant biology has the potential to contribute greatly to reducing health care costs as well as playing an integral role in discovery of new drugs and therapies. *Although the National Institutes of Health does offer some funding support to plant biology research, with increased funding plant biologists can offer much more to advance the missions of the National Institutes of Health.* In the next section, we highlight the particular relevance of plant biology research to human health.

Plant Biology and the National Institutes of Health

The mission of the NIH is to pursue “fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.” Plant biology research is highly relevant to this mission.

Plants are often the ideal model systems to advance our “fundamental knowledge about the nature and behavior of living systems,” as they provide the context of multi-cellularity while affording ease of genetic manipulation, a lesser regulatory burden, and inexpensive maintenance requirements. Many basic biological components and mechanisms are shared by both plants and animals. For example, a molecule named cryptochrome that senses light was identified first in plants and subsequently found to also function in humans, where it plays a central role in regulating our biological clock. Jet lag provides one familiar example of what happens to us when our biological clock is disrupted, but there are also human genetic disorders that have been linked to malfunctioning of the clock. As another example, some fungal pathogens can infect both humans and plants, and the molecular mechanisms employed by both the pathogen and its targeted host can be very similar.

Health and Nutrition

Plant biology research is also central to the application of basic knowledge to “extend healthy life and reduce the burdens of illness and disability.” This connection is most obvious in the inter-related areas of nutrition and clinical medicine. Without good nutrition, there cannot be good health. Indeed, one World Health Organization study on childhood nutrition in developing countries concluded that over 50% of the deaths of children less than five years of age could be attributed to malnutrition's effects in exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition but only to mild or moderate nutritional deficiencies. Plant biology researchers are working today to improve the nutritional content of crop plants by, for example, increasing the availability of nutrients and vitamins such as iron, vitamin E and vitamin A. (Up to 500,000 children in the developing world go blind every year as a result of vitamin A deficiency).

By contrast, obesity, cardiac disease, and cancer take a striking toll in the developed world. Among many plant biology initiatives relevant to these concerns are research to improve the lipid composition of plant fats and efforts to optimize concentrations of plant compounds that are known to have anti-carcinogenic properties, such as the glucosinolates found in broccoli and cabbage, and the lycopenes found in tomato. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists are making toward realizing the goal of personalized medicine, especially personalized preventative medicine.

Drug Discovery

Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, over 10% of the drugs considered by the World Health Organization to be “basic and essential” are still exclusively obtained from flowering plants. Some historical examples are quinine, which is derived from the bark of the cinchona tree and was the first highly effective anti-malarial drug; and the plant alkaloid morphine, which revolutionized the treatment of pain.

These pharmaceuticals are still in use today. A more recent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol. The discovery of taxol came about through collaborative work involving scientists at the National Cancer Institute within NIH and plant biologists at the U.S. Department of Agriculture. The plant biologists collected a wide diversity of plant materials, which were then evaluated for anti-carcinogenic properties. It was found that the bark of the Pacific yew tree yielded one such compound, which was isolated and named taxol after the tree’s Latin name, *Taxus brevifolia*. Originally, taxol could only be obtained from the tree bark itself, but additional research led to the elucidation of its molecular structure and eventually to its chemical synthesis in the laboratory.

On the basis of a growing understanding of metabolic networks, plants will continue to be sources for the development of new medicines to help treat cancer and other ailments. Taxol is just one example of a plant secondary compound. Since plants produce an estimated 200,000 such compounds, they will continue to provide a fruitful source of new drug leads, particularly if collaborations such as the one described above can be fostered and funded. With additional research support, plant biologists can lead the way to developing new medicines and biomedical applications to enhance the treatment of devastating diseases.

Conclusion

Despite the fact that plant biology research underlies so many vital practical considerations for our country, the amount invested in understanding the basic function and mechanisms of plants is small when compared with the impacts of this information on multibillion dollar sectors of the economy such as health, energy, and agriculture.

Clearly, the NIH does recognize that plants are a vital component of its mission. However, because the boundaries of plant biology research are permeable and because information about plants integrates with many different disciplines that are highly relevant to NIH, *ASPB hopes that the Subcommittee will provide additional resources through increased funding to NIH for plant biology in order to help pioneer new discoveries and new methods in biomedical research.*

Thank you for your consideration of our testimony on behalf of the American Society of Plant Biologists. Please do not hesitate to contact the American Society of Plant Biologists if we can be of any assistance in the future.

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**Written Testimony Submitted to the House
Labor, Health and Human Services, and Education Appropriations Subcommittee
Regarding FY 2011 Funding for Malaria and Neglected Tropical Disease Programs**

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The American Society of Tropical Medicine and Hygiene (ASTMH) – the principal professional membership organization representing, educating, and supporting scientists, physicians, clinicians, researchers, epidemiologists, and other health professionals dedicated to the prevention and control of tropical diseases – appreciates the opportunity to submit written testimony to the House Labor, Health and Human Services, and Education Appropriations Subcommittee. We respectfully request that the Subcommittee provide the following allocations in the FY 2011 Labor, Health and Human Services, and Education Appropriations bill to support a comprehensive effort to promote malaria, neglected tropical disease (NTD), and diarrheal disease control programming globally:

- \$35 billion to the National Institutes of Health (NIH);
- \$5.04 billion to the National Institute of Allergy and Infectious Diseases (NIAID);
- \$78.5 million to the Fogarty International Center (FIC);
- \$18 million to the Centers for Disease Control and Prevention (CDC) for malaria research, control, and program evaluation efforts with a \$6 million set-aside for program monitoring and evaluation; and
- Direct funding to the CDC for ongoing efforts on NTDs and diarrheal disease.

ASTMH Background

The 3,700 members of the Society work in a myriad of public, private, and non-profit environments. The largest proportion of our membership (34%) work in academia at the nation's leading research universities. Fifteen percent of ASTMH members are employed by the U.S. military, and 11% are employed in public institutions and federal agencies. Nine percent of ASTMH members are in private practice, with another four percent working in industry (e.g. pharmaceutical companies). The balance of the ASTMH membership works in numerous other capacities and for various other entities seeking to reduce and prevent tropical disease.

Tropical Medicine and Tropical Diseases

The term “tropical medicine” refers to the wide-ranging clinical, research, and educational efforts of physicians, scientists, and public health officials with a focus on the diagnosis, mitigation, prevention, and treatment of vector borne diseases prevalent in the areas of the world with a tropical climate. Most tropical diseases are located in either sub-Saharan Africa, parts of Asia (including the Indian subcontinent), or Central and South America. Many of the world's developing nations are located in these areas; thus tropical medicine tends to focus on diseases that impact the world's most impoverished individuals.

ASTMH aims to advance policies and programs that prevent and control those tropical diseases which particularly impact the global poor. The United States has a long history of leading the fight against tropical diseases which cause human suffering and pose a great financial burden that can negatively impact a country's economic and political stability. The benefits of US investment in tropical diseases are not only humanitarian, they are diplomatic as well. ASTMH members and others work to reduce the impact of tropical diseases and to directly and positively impact populations that are otherwise generally ignored, but on whom many countries' futures depend. Tropical diseases, many of them neglected for decades, impact US citizens working or traveling overseas as well as our military personnel. Furthermore, some of the agents responsible for these diseases can be introduced and become established in the US (as was the case with West Nile virus), or might even be weaponized.

Malaria

Malaria remains a global emergency affecting mostly poor women and children; it is an acute, sometimes fatal disease caused by the single-celled *Plasmodium* parasite transmitted to humans by *Anopheles* mosquitoes. Malaria can cause anemia, jaundice, kidney failure, and death. Despite being treatable and preventable, malaria is one of the leading causes of death and disease worldwide. Approximately every 30 seconds, a child dies of malaria – a total of about 800,000 under the age of 5 every year. (During the time it took to read this message, 10 children have died.)

The World Health Organization (WHO) estimates that one half of the world's people are at risk for malaria and that there are 108 malaria-endemic countries. Malaria-related illness and mortality not only take a human toll, they severely impact economic productivity and growth. The WHO has estimated that malaria reduces sub-Saharan Africa's economic growth by up to 1.3 percent per year.

Fortunately, malaria can be both prevented and treated using four types of relatively low-cost interventions: (1) the indoor residual spraying (IRS) of insecticide on the walls of homes; (2) long-lasting insecticide-treated nets (LLIN); (3) Artemisinin-based combination therapies (ACTs); and (4) intermittent preventive therapy (IPT) for pregnant women in areas with high transmission. However, limited resources preclude the provision of these interventions and treatments to all individuals and communities in need. Thus, ASTMH calls upon Congress to fund a comprehensive approach to malaria control, including public health infrastructure improvements, mosquito abatement initiatives, and increased availability of existing anti-malarial drugs, development of new anti-malarial drugs and better diagnostics, and research to identify an effective malaria vaccine.

Neglected Tropical Diseases, Diarrheal Disease and Arboviruses

According to WHO, over 1 billion people – one-sixth of the world's population – suffer from one or more NTDs, including arboviruses such as yellow fever and Dengue fever. The pediatric death toll due to diarrheal illnesses exceeds that of AIDS, tuberculosis, and malaria combined. In poor countries, diarrheal disease is second only to pneumonia in causing the deaths of children

under five years old. Every week, 31,000 children in low-income countries die from diarrheal diseases. Diarrheal and NTDs, including arboviruses, are a symptom of poverty and disadvantage. Most of those affected are the poor populations in rural areas, urban slums or conflict zones. Traditionally, these diseases have been neglected by the world.

Requested Activities and Funding Levels

National Institute of Allergy and Infectious Diseases (NIAID): Malaria continues to be among the most daunting global public health challenges we face and one sixth of the world's population suffers from one or more NTDs. A long-term investment is needed to achieve the drugs, diagnostics and research capacity needed to control malaria and neglected tropical disease. NIAID, the lead institute for malaria research, plays an important role in developing the drugs and vaccines needed to fight malaria.

Malaria: NIH estimates spending approximately \$152 million overall with for malaria research and \$36 million for research related specifically to creating a malaria vaccine in FY 2011. NIAID, the lead institute for this research, has developed an Implementation Plan for Global Research on Malaria, which is focused on five research areas: vaccine development, drug development, diagnostics, vector control, and infrastructure and research capability strengthening.

NTDs: The NIH, through NIAID conducts research to better understand NTDs, which includes conducting its own basic and clinical studies as well as extramural research. These efforts include:

- Research at the NIAID Laboratory of Parasitic Diseases to uncover how NTD-causing pathogens interact with humans, animals, and the organisms that spread them from host to host. The lab conducts patient-centered research at the NIH Clinical Center in Bethesda, MD, as well as field studies in India, Latin America, and Africa.
- Actively supporting the discovery and development of drugs for NTDs including a low-cost treatment for visceral leishmaniasis and identifying new drugs for sleeping sickness and Chagas disease.
- The Vector Biology Research Program at NIAID supports research on several vectors that transmit agents of NTDs. Many of these projects have field components in disease-endemic areas of the world.
- NIAID also has research repositories that provide researchers with parasite species, standard study protocols, and training.

ASTMH encourages NIH to continue and expand its investment in malaria, NTD, diarrheal disease, and arbovirus research and to coordinate that work with other government agencies to maximize resources and ensure development of basic discoveries into useable solutions. NIAID is at the forefront of these efforts and continued funding is crucial to developing the next generation of drugs, vaccines, and other interventions.

Fogarty International Center (FIC): Although biomedical research has provided major advances in the treatment and prevention of malaria, neglected tropical diseases and other infectious diseases, these benefits are often slow to reach the people who need them most. Highly-effective anti-malarial drugs exist; when patients receive these drugs promptly, their lives can be saved. FIC plays a critical role in strengthening science and public health research institutions in low-income countries. For example, for nearly a decade FIC has funded a program that has produced a substantial number of researchers with the expertise to address the research and clinical challenges associated with diarrheal diseases in Latin America. This strong international collaboration is fostering new discoveries on the long-term effects of and treatments for diarrheal diseases. By promoting applied health research in developing countries, the FIC can speed the implementation of new health interventions for malaria and NTDs.

FIC works to strengthen research capacity in countries where populations are particularly vulnerable to threats posed by malaria and neglected tropical diseases. FIC efforts that strengthen the research workforce in-country – including collaborations with U.S.-supported global health programs – help to ensure the continuous improvement of programs, adapting them to local conditions. This maximizes the impact of U.S. investments and is critical to fighting malaria and other tropical diseases.

FIC addresses global health challenges and supports the NIH mission through many activities, including:

- collaborative research and capacity building projects relevant to low- and middle-income nations;
- institutional training grants designed to enhance research capacity in the developing world, with an emphasis on institutional partnerships and networking;
- the Forum for International Health, through which NIH staff share ideas and information on relevant programs and develop input from an international perspective on cross-cutting NIH initiatives;
- the Multilateral Initiative on Malaria, which fosters international collaboration and co-operation in scientific research against malaria; and
- the Disease Control Priorities Project, a partnership supported by FIC, the Bill & Melinda Gates Foundation, the WHO, and the World Bank to develop recommendations on effective health care interventions for resource-poor settings.

ASTMH urges the Subcommittee to allocate additional resources to the FIC in FY 2011 to increase these efforts, particularly as they address the control and treatment of malaria, NTDs and diarrheal disease.

CDC Malaria Efforts: ASTMH calls upon Congress to fund a comprehensive approach to malaria control, including adequately funding the important contributions of CDC. CDC originally grew out of the WWII “Malaria Control in War Areas” program. Since its founding, the Atlanta-based agency has maintained a strong role in efforts to research and mitigate malaria. Although malaria has been eliminated as an endemic threat in the United States for over fifty years, CDC remains on the cutting edge of global efforts to reduce the toll of this deadly disease.

The CDC is crucial partner in the President's Malaria Initiative (PMI), a \$6.2 billion, nine-year effort led by the U.S. Agency for International Development (USAID) in conjunction with CDC and other government agencies to lower the incidence of malaria in 15 targeted countries in sub-Saharan Africa by 50 percent.

CDC efforts on malaria fall into three broad areas – prevention, treatment, and monitoring/evaluation. The agency performs a wide range of basic research within these categories, such as:

- Providing technical assistance to malaria-endemic, non-PMI countries;
- Conducting research on long-lasting insecticide-treated nets (LLINs), indoor residual spraying (IRS), malaria in pregnancy (MIP), and case management including diagnosis, treatment and antimalarial drug resistance to inform new strategies and prevention approaches;
- Assessing new monitoring, evaluation and surveillance strategies;
- Conducting additional research on malaria vaccines, including field evaluations; and
- Developing novel public health strategies for improving access to antimalarial treatment and delaying the appearance of antimalarial drug resistance.

CDC NTD Programs: CDC has had a long history of working on NTDs and has provided much of the science that underlies those global policies and programs in existence today. ASTMH encourages the Subcommittee to provide direct funding to the CDC to continue its work on NTDs, diarrheal diseases, and arboviruses, such as Japanese encephalitis and Dengue. This work is important to any global health initiative as individuals are often infected with multiple NTDs simultaneously. It is essential that CDC be encouraged to continue its monitoring, evaluation and technical assistance in these areas as an underpinning of efforts to control and eliminate these diseases. Currently the CDC receives zero dollars directly for NTD work; however this should be changed to allow for more comprehensive work to be done on NTDs directly at the CDC.

Conclusion

Thank you for your attention to these important global health matters. We know you face many challenges in choosing funding priorities, and we hope you will provide the requested FY 2011 resources to those programs identified above. ASTMH appreciates the opportunity to share its views, and we thank you for your consideration of our requests.



AMERICANS FOR NURSING SHORTAGE RELIEF

Testimony of the Americans for Nursing Shortage Relief (ANSR) Alliance Regarding Fiscal Year 2011 Appropriations for Title VIII - Nursing Workforce Development Programs

Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

April 15, 2010

The undersigned organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony regarding fiscal year (FY) 2011 appropriations for Title VIII – Nursing Workforce Development Programs. We represent a diverse cross-section of health care and other related organizations, health care providers, and supporters of nursing issues that have united to address the national nursing shortage. ANSR stands ready to work with the Congress to advance programs and policy that will ensure that our nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century. The Alliance, therefore, urges Congress to:

- **Appropriate \$267.3 million in funding in FY 2011 for the Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at the Health Resources and Services Administration (HRSA).**
- **Direct the requested increase at the Title VIII programs that have not kept pace with inflation since FY 2005: Advanced Education Nursing, Nursing Workforce Diversity, Nurse Education, Practice and Retention, and Comprehensive Geriatric Education. These programs, which help expand nursing school capacity and increase patient access to care, would greatly benefit from the 10% increase awarded in proportion to their FY 2010 funding levels.**

The Extent of the Nursing Shortage

Nursing is the largest health care profession in the United States. According to the National Council of State Boards of Nursing, there were nearly 3.733 million licensed RNs in 2008.¹ Nurses and advanced practice nurses (nurse practitioners, nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists) work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, and hospitals. In 2008, 60 percent of RN jobs were in hospitals.² About 8 percent of RN jobs were in physician offices, 5 percent in home healthcare services, 5 percent in nursing care facilities, and 3 percent in employment services. The remainder worked

¹ National Council of State Boards of Nursing, (2010). *2008 Nurse Licensee Volume and NCLEX® Examination Statistics. (Research Brief Vol. 42)*. On the Internet at: https://www.ncsbn.org/10_2008NCLFExamStats_Vol42_web_links.pdf (Accessed March 15, 2010).

² Bureau of Labor Statistics, U.S. Department of Labor. *Occupational Outlook Handbook, 2010-11 Edition, Registered Nurses*. On the Internet at: <http://www.bls.gov/oco/ocos083.htm> (Accessed February 26, 2010).

mostly in government agencies, social assistance agencies, and education services. A federal report published in 2004 estimates that by 2020 the national nurse shortage will increase to more than one million full-time nurse positions. According to these projections, which are based on the current rate of nurses entering the profession, only 64 percent of projected demand will be met.³ A study, published in March 2008, uses different assumptions to calculate an adjusted projected demand of 500,000 full-time equivalent registered nurses by 2025.⁴ According to the U.S. Bureau of Labor Statistics, employment of registered nurses is expected to grow by 22 percent from 2008 to 2018, much faster than the average for all occupations and, because the occupation is very large, 581,500 new jobs will result. Based on these scenarios, the shortage presents an extremely serious challenge in the delivery of high-quality, cost-effective services, as the nation looks to reform the current healthcare system. Even considering only the smaller projection of vacancies, this shortage still results in a critical gap in nursing service, essentially three times the 2001 nursing shortage.

Building the Capacity of Nursing Education Programs

Nursing vacancies exist throughout the entire health care system, including long-term care, home care and public health. Even the Department of Veterans Affairs, the largest sole employer of RNs in the U.S., has a nursing vacancy rate of 10 percent. In 2006, the American Hospital Association reported that hospitals needed 116,000 more RNs to fill immediate vacancies, and that this 8.1 percent vacancy rate affects hospitals' ability to provide patient/client care.⁵ Government estimates indicate that this situation only promises to worsen due to an insufficient supply of individuals matriculating in nursing schools, an aging existing workforce, and the inadequate availability of nursing faculty to educate and train the next generation of nurses. At the exact same time that the nursing shortage is expected to worsen, the baby boom generation is aging and the number of individuals with serious, life-threatening, and chronic conditions requiring nursing care will increase. Consequently, more must be done now by the government to help ensure an adequate nursing workforce for the patients/clients of today and tomorrow.

A particular focus on securing and retaining adequate numbers of faculty is essential to ensure that all individuals interested in – and qualified for – nursing school can matriculate in the year they are accepted. The National League for Nursing found that in the 2007-2008 academic year, 119,000 qualified applications – or 39 percent of all qualified applications submitted to nursing education programs – were denied due to lack of capacity. Baccalaureate degree programs turned away 24 percent of its applications, while associate degree programs turned away 42 percent.⁶ Aside from having a limited number of faculty, nursing programs struggle to provide space for clinical laboratories and to secure a sufficient number of clinical training sites at health care facilities.

³ Health Resources and Services Administration, (2004). *What is Behind HRSA's Projected Supply, Demand, and Shortage of Registered Nurses?* On the Internet at: <http://bhpr.hrsa.gov/healthworkforce/reports/behindrprojections/4.htm>. (Accessed February 26, 2010).

⁴ Buerhaus, P., Staiger, D., Auerbach, D. (2008). *The Future of the Nursing Workforce in the United States: Data, Trends, and Implications*. Boston, MA: Jones & Bartlett.

⁵ American Hospital Association, (2007) *The State of America's Hospitals: Taking the Pulse, Findings from the 2007 AHA Survey of Hospital Leaders*. On the Internet at: <http://www.aha.org/aha/content/2007/PowerPoint/StateofHospitalsChartPack2007.ppt>. (Accessed December 3, 2008).

⁶ National League for Nursing, (2010). *Nursing Data Review 2007-2008: Baccalaureate, Associate Degree, and Diploma Programs*. On the Internet at: <http://www.nln.org/research/slides/index.htm>. (Accessed February 26, 2010).

The Alliance supports the need for sustained attention on the efficacy and performance of existing and proposed programs to improve nursing practices and strengthen the nursing workforce. The support of research and evaluation studies that test models of nursing practice and workforce development is integral to advancing health care for all in America. Investments in research and evaluation studies have a direct effect on the caliber of nursing care. Our collective goal of improving the quality of patient/client care, reducing costs, and efficiently delivering appropriate health care to those in need is served best by aggressive nursing research and performance and impact evaluation at the program level.

The Impact on the Nation's Public Health Infrastructure

The National Center for Health Workforce Analysis reports that the nursing shortage challenges the health care sector to meet current service needs. Nurses make a difference in the lives of patients/clients from disease prevention and management to education to responding to emergencies. Chronic diseases, such as heart disease, stroke, cancer, and diabetes, are the most preventable of all health problems as well as the most costly. Nearly half of Americans suffer from one or more chronic conditions and chronic disease accounts for 70 percent of all deaths. In addition, increased rates of obesity and chronic disease are the primary cause of disability and diminished quality of life.

Even though America spends more than \$2 trillion annually on health care – more than any other nation in the world – tens of millions of Americans suffer every day from preventable diseases such as type 2 diabetes, heart disease, and some forms of cancer that rob them of their health and quality of life.⁷ In addition, major vulnerabilities remain in our emergency preparedness to respond to natural, technological and manmade hazards. An October 2008 report issued by Trust for America's Health entitled "Blueprint for a Healthier America" found that the health and safety of Americans depends on the next generation of professionals in public health.⁸ Further, existing efforts to recruit and retain the public health workforce are insufficient. New policies and incentives must be created to make public service careers in public health an attractive professional path, especially for the emerging workforce and those changing careers.

An Institute of Medicine report notes that nursing shortages in U.S. hospitals continue to disrupt hospitals operations and are detrimental to patient/client care and safety.⁹ Hospitals and other health care facilities across the country are vulnerable to mass casualty incidents themselves and/or in emergency and disaster preparedness situations. As in the public health sector, a mass casualty incident occurs because of an event where sudden and high patient/client volume exceeds the facilities/sites resources. Such events may include the more commonly realized multi-car pile-ups, train crashes, hazardous material exposure in a building or within a community, high occupancy catastrophic fires, or the extraordinary events such as pandemics, weather-related disasters, and intentional catastrophic acts of violence. Since 80 percent of disaster victims present at the emergency department, nurses as first receivers are an important aspect of the public health system as well as

⁷ KaiserEDU.org. "U.S. Health Care Costs: Background Brief." Kaiser Family Foundation. On the Internet at: <http://www.kaiseredu.org/topics_im.asp?urlID=1&parentID=61&id=358> (Accessed November 24, 2008).

⁸ Trust for America's Health. (2008) *Blueprint for a Healthier America: Modernizing the Federal Public Health System to Focus on Prevention and Preparedness*. On the Internet at: <http://healthamericans.org/report/55/blueprint-for-healthier-america> (Accessed December 3, 2008).

⁹ Institute of Medicine. Committee on the Future of Emergency Care in the United States Health System. (2007) *Hospital-Based Emergency Care: At the Breaking Point*. On the Internet at: <http://www.iom.edu/?id=48826>. (Accessed December 3, 2008).

the healthcare system in general. The nursing shortage has a significant adverse impact on the ability of communities to respond to health emergencies, including natural, technological and manmade hazards.

Summary

The link between health care and our nation's economic security and global competitiveness is undeniable. Having a sufficient nursing workforce to meet the demands of a highly diverse and aging population is an essential component to reforming the health care system as well as improving the health status of the nation and reducing health care costs. To mitigate the immediate effect of the nursing shortage and to address all of these policy areas, ANSR requests \$267.3 million in funding for the Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at HRSA in FY 2011. The requested increase should be directed at the Title VIII programs that have not kept pace with inflation since FY 2005: Advanced Education Nursing, Nursing Workforce Diversity, Nurse Education, Practice and Retention, and Comprehensive Geriatric Education. These programs, which help expand nursing school capacity and increase patient access to care, would greatly benefit from the 10% increase awarded in proportion to their FY 2010 funding levels.

Academy of Medical-Surgical Nurses
 American Academy of Ambulatory Care Nursing
 American Academy of Nurse Practitioners
 American Academy of Nursing
 American Association of Critical-Care Nurses
 American Association of Nurse Anesthetists
 American Association of Nurse Assessment Coordinators
 American Association of Nurse Executives
 American Association of Occupational Health Nurses
 American College of Nurse Practitioners
 American Organization of Nurse Executives
 American Psychiatric Nurses Association
 American Society for Pain Management Nursing
 American Society of PeriAnesthesia Nurses
 American Society of Plastic Surgical Nurses
 Association for Radiologic & Imaging Nursing
 Association of Pediatric Hematology/Oncology Nurses
 Association of periOperative Registered Nurses
 Association of Rehabilitation Nurses
 Association of State and Territorial Directors of Nursing
 Association of Women's Health, Obstetric & Neonatal Nurses
 Citizen Advocacy Center
 Developmental Disabilities Nurses Association
 Emergency Nurses Association
 Gerontological Advanced Practice Nurses Association
 Infusion Nurses Society
 International Society of Nurses in Genetics, Inc.

Legislative Coalition of Virginia Nurses
National Association of Clinical Nurse Specialists
National Association of Hispanic Nurses
National Association of Neonatal Nurses
National Association of Neonatal Nurse Practitioners
National Association of Nurse Massage Therapists
National Association of Nurse Practitioners in Women's Health
National Association of Orthopaedic Nurses
National Association of Pediatric Nurse Practitioners
National Association of Registered Nurse First Assistants
National Black Nurses Association
National Council of State Boards of Nursing
National Council of Women's Organizations
National Gerontological Nursing Association
National League for Nursing
National Nursing Centers Consortium
National Nursing Staff Development Organization
National Organization for Associate Degree Nursing
National Organization of Nurse Practitioner Faculties
National Student Nurses' Association, Inc.
Nurses Organization of Veterans Affairs
Pediatric Endocrinology Nursing Society
RN First Assistants Policy & Advocacy Coalition
Society of Gastroenterology Nurses and Associates, Inc.
Society of Pediatric Nurses
Society of Trauma Nurses
Women's Research & Education Institute
Wound, Ostomy and Continence Nurses Society

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TESTIMONY

**House Appropriations Subcommittee on Labor, Health and Human Services,
 Education, and Related Agencies**

Fiscal Year 2011

Submitted by Cathy Liss, President (cathy@awionline.org)

April 16, 2010

As part of the Fiscal Year 2010 appropriations bill for the National Institutes of Health (NIH), both the House of Representatives and the Senate included language in their reports directing NIH to take steps to end the use of Class B dealers by its grant recipients. Grantees affected by this language are small in number. According to USDA, for the period November 2007-November 2008, 2,863 dogs and 276 cats from Class B dealers were sold for research. This constitutes just 3 percent of the almost 95,000 total dogs and cats used in FY2007 for all research purposes, which include not only NIH-sponsored research, but also non-NIH-related research, testing and teaching.

Both chambers were responding to a report from the National Academy of Sciences (NAS) ("Scientific and Humane Issues in the Use of Random Source Dogs and Cats in Research"), undertaken at the request of Congress, that "critically examine[d] the general desirability and necessity of using random source dogs and cats in NIH-funded research, and the specific necessity of using Class B dealers as a source of such animals for NIH-funded research." (p.2) While the Committee "concluded that under some circumstances, dogs and cats with qualities of random source animals may be desirable and necessary for NIH-funded research," it also "determined Class B dealers are not necessary as providers of random source animals for NIH-related research" (p.5) and that adequate numbers of such animals are available from other sources.

NIH has been dragging its feet in addressing the problem of Class B dealers for a decade, since this Subcommittee first expressed its concern over the matter to NIH. Based on statements NIH representatives have made with respect to the NAS report and the appropriations report language, we expect them to continue dragging their feet. **We respectfully request that the Subcommittee follow up the recommendations it included in its FY2010 report language with statutory language prohibiting NIH from awarding or renewing any grants or contracts that involve the use of dogs or cats acquired from class B dealers, and that, moreover, NIH immediately begin supporting alternative sources of random-source dogs and cats from non-Class B dealers.**

It should be clarified that the NAS report addressed extramural research funded by NIH, not NIH's internal research endeavors. The irony is, NIH ceased using Class B dealers in its own intramural research over 20 years ago, recognizing the problems—both ethical and scientific—caused by acquiring dogs from sources that treat the animals inhumanely; fail to provide proper veterinary care and the basic necessities such as clean water, food, and

shelter; acquire animals through fraud and deception; and are constantly under investigation for violations of the Animal Welfare Act (AWA). In fact, in a recent article in *Science* (David Grimm, "Dog Dealers' Days May Be Numbered," Vol.327, 26 February 2010, p. 1076-1077), Dr. Robert Whitney, former director of NIH's National Center for Research Resources (1972-1992) and Deputy Surgeon General of the U.S. Public Health Service (1992), is quoted as saying, "By using these animals, we risk losing our credibility with the public. It's an Achilles' heel for research." Even so, NIH steadfastly refuses to hold its extramural grant recipients to the same high standard it requires of its intramural researchers.

Of the 10 remaining licensed Class B dealers who sell live random source dogs and cats for experimentation, one is presently under a 5-year license suspension, and 6 are under investigation for AWA violations. And welfare problems with licensed Class B dealers are myriad. Needed veterinary care is lacking for many random source animals. Heartworm is a widespread problem, particularly in the South. Hookworm and mange are as well. Inspectors have observed animals at dealer premises with mange, "loose stool with some blood," "ring-worm like lesions," infected eyes, bite wounds, lameness, tumors, chronic cough, and animals who are severely underweight and others with a "purulent discharge from the nose." In most cases, there is no record of any veterinary care.

Research institutions may reject animals delivered by a dealer because of the poor condition of the dogs and cats, leaving them to be hauled from location to location to see if there will be a taker. If not, the animal may be taken back and left to die or simply shot. Some at research institutions have let USDA know of their concerns. One such email identified a cat "in very poor condition: cache[c]tic, severely matted hair coat and a severe case of ear mites." It went on to note that "many of the cats that we receive are wild or are almost wild. I do not understand where these cats come from and how they are examined for health certificates. I thought the animals had to come from someone who had raised and bred the animals on their property or from a specific shelter."

The conditions for housing, feeding, and care can be problematic as well. An Ohio dealer was cited for "contaminated straw, wet with urine and excessive feces. Excessive flies. Water receptacles contaminated with black and green algae—a thick layer." A dealer in Indiana had dogs unable to avoid contact with excreta. Another dealer's inspection report notes, "Some 70-75% dogs have water and bread and little bits of dog food floating in water. There were some dogs that had only bread and water. Some had dog food floating in water. Most of dogs had not eaten the watery food blend....About 70% of the total dogs had non-potable water. Water was mixed with bread and dog food and sitting in the direct sun."

The NAS report took note of these failures to provide for the animals' basic welfare: "In addition, the Committee determined that the husbandry standards and humane treatment of animals was unacceptably variable among existing Class B dealers, **and not commensurate with NIH standards of research animal care and quality.**" (p. 86; emphasis added.) The report also observed that "random source dogs and cats used for research probably endure greater degrees of stress and distress compared to purpose-bred

animals. This conclusion has implications not only for the welfare of random source animals but also for their overall reliability as research models.” (p.59)

USDA is also pursuing separate investigations regarding apparent supply violations identified during tracebacks conducted of dealer records necessitated by ongoing questions about the illegality of the sources of animals. Unlike any other licensees covered under the AWA, this one group—Class B dealers selling dogs and cats for research—has a long-standing problem maintaining complete and accurate records. An insurmountable hurdle for USDA is that the AWA allows anyone who *claims* to have bred and raised an animal to profit by selling the animal to a random source dealer—and how can USDA be expected to disprove it?

Complicating matters further is the fact that dealers commonly network with each other; that is, animals are sold from buncher (an unlicensed dealer who literally bunches together animals from various sources) to dealer to another dealer, often across multiple state lines, before being sold for research. With animals changing hands and being shipped across the country, how is USDA supposed to keep up with the movement of animals and verify their source? The NAS report called it a “complicated tangle of trade” (p.11).

Another shell game dealers like to play is passing the business on to other members of the family after showing them the ropes. Sometimes a former employee of a dealer, who has also learned how to work the system, may go off on his own and get licensed as well. Brothers Danny and Johnny Schachtele of Missouri ran their licensed Class B dealer operation as a team beginning in 1987. Later Johnny left the business and Danny’s wife, Mildred, replaced him. Over the ensuing years, the husband-wife team were cited by USDA for a host of violations of the AWA, and they were charged with a laundry list of violations, including failure to maintain records that fully and correctly disclose the identities and other required information of the persons from whom dogs were acquired on 51 separate occasions, including one incident that pertained to 43 dogs. Further, they were charged with failing to provide complete certifications on seven separate occasions, including one that pertained to 195 dogs. The husband died before the case was resolved and though the wife was fined \$107,250, the judge suspended \$100,000 of it. But the story doesn’t end here.

The couple’s son and daughter-in-law, after helping mom close down her business, set up their own Class B dealer operation. Becky and Tony Schachtele have been cited repeatedly by USDA for apparent violations including inadequate veterinary care, faulty record-keeping, inadequate cleaning and sanitization, and problems with housing and primary enclosures. Among multiple dogs in need of veterinary care, the USDA inspector noted one dog “standing with its head down and rocking in an abnormal manner from front to back and side to side...dull eyes...never lifted its head...was very thin with very prominent, easily visible bony structures...the dogs abdomen was extremely tucked and its hair coat was dull.” At one inspection alone, 48 records had incomplete addresses for the persons who sold the animals; 31 animal certification forms were incomplete; and 44 forms had inconsistent and therefore inaccurate information regarding the animals and when they

were acquired and sold. Though under investigation, the Schachteles are still selling dogs and cats for research.

During a House Agriculture Subcommittee hearing held back in 1996, then-Assistant Secretary of Agriculture Michael Dunn described his frustration with random source dealers: "Every time we develop a new way to look for something, they develop a new way to hide it." To address these numerous and ongoing violations, USDA has to inspect random source dealers four times a year instead of once a year as is done with all other licensees and registrants under the AWA. It spends approximately \$300,000 per year trying to regulate this small number of dealers, and even with that, the department acknowledged in its NAS testimony that it cannot guarantee that stolen pets are not being sold into research. The NAS report pointed to "loopholes" by which pets might enter the "research pipeline," calling even single incidents "an undeniable breach of the public trust." (p.78)

The effect on the animals of such inhumane treatment, and the costs of enforcement, are not included in the calculation when NIH cites the cheaper cost of random source dogs and cats acquired from Class B dealers. But the NAS report does take these things into account: "...[O]ftentimes dogs and cats from Class B dealers are not free from disease. In addition to being a potential threat to other animals and people in the research facility, they may need to undergo prolonged quarantine, socialization, treatment, or be removed from the study all together [sic]. These hidden costs may substantially increase the actual final cost by hundreds of dollars per animals. Additionally, the price of USDA/APHIS oversight of Class B dealers...represents a substantial cost to the U.S. government and ultimately the American public that is not incurred by NIH, the research institution, nor the research investigator." (p.75)

Ultimately, "the [NAS] Committee could not reconcile the serious unresolved Class B compliance issues, and felt that these issues, as well as humane concerns, were major factors in the Committee's final recommendations." (p.82)

The AWA was passed in 1966 to address the illegal supply of dogs and cats to laboratories, and now, over four decades later, these problems are still widespread. What has changed significantly over this lengthy period of time is the availability of animals from suppliers other than random source dealers. Given the problems inherent in the use of licensed Class B dealers, researchers have increasingly and successfully shifted to acquiring most of their dogs and cats from licensed Class A breeders—and by using these dealers instead, the researchers will receive animals who have been raised under controlled conditions, with the health and vaccination status and the genetic background on each individual animal known. In addition, some dogs and cats are being bred for experimentation at registered research facilities, and in some cases, inexpensive random type animals are purchased directly from animal pounds.

NIH has told this Subcommittee that it is "committed to ensuring the appropriate care and use of animals in research." However, NIH has left the decision of whether or not to buy dogs and cats from random source dealers "to the local level on the basis of scientific need." NIH defends the use of Class B dealers arguing that these dealers are needed to obtain

“animals that may not be available from other sources, such as genetically diverse, older, or larger animals.” The National Academies report clearly states that “it is not necessary to acquire them [random source dogs and cats] through Class B dealers,” (“Report In Brief”), and that adequate numbers are available through alternative sources.

All animals used in research should be obtained from lawful sources. Taxpayer dollars, in the form of NIH extramural grants, must not continue to fund research using dogs and cats from dealers whose *modus operandi* involves illegal acquisition of animals, fraudulent or incomplete records and other illicit activities, and failure to abide by the minimum care requirements of the AWA.

Thank you very much for your consideration of our request for statutory language to address this issue and put an end to wasting taxpayer money on propping up this corrupt system.

**Ann D. Peel
Private Citizen
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STATEMENT ON AMYLOIDOSIS
BY
ANN D. PEEL
PRIVATE CITIZEN, BETHESDA, MARYLAND
BEFORE
THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES
APRIL 16, 2010

Summary: The testimony asks the Committee to include report language calling for additional steps to be taken on the diagnosis, treatment and research on the rare and deadly disease amyloidosis. The testimony also asks that additional research and treatment equipment for amyloidosis be provided for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center.

Mr. Chairman, I appreciate the opportunity to submit testimony to the Committee on the life threatening disease amyloidosis. I ask that you continue to include language in the Committee's report for fiscal year 2011 drawing attention to amyloidosis. I also request that you recommend assistance for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center.

In previous testimony before this Committee, I identified my efforts to combat the life-threatening disease primary amyloidosis. I have successfully obtained treatment for amyloidosis. Now I want to devote time to use my experience to help others.

Amyloidosis, which is often fatal, leads to heart, kidney, liver and other organ failure. Amyloidosis can literally kill people before they know what hit them. Left untreated there is an average survival rate from the time of diagnosis of about 15 months.

Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis. The small number of those with amyloidosis who are able to obtain treatment may face the risk of high dose chemotherapy and stem cell replacement.

Less than one percent of the U. S. population has been identified to have this disease. Many feel that the disease is vastly underdiagnosed, especially in the African-American community.

AMYLOIDOSIS

Amyloidosis occurs when cells malfunction and produce proteins that deposit on organs, such as the heart, kidney and liver. These misfolded proteins clog the organs until they no longer are able to function—sometimes at a very rapid pace.

In addition to primary amyloidosis, there are also cases of inherited or familial amyloidosis and secondary or reactive amyloidosis. All three types of amyloidosis, left undiagnosed or untreated, are fatal.

There is no explanation for how or why amyloidosis develops and there is no known cure.

AMYLOIDOSIS TREATMENT

Boston University School of Medicine and other centers for amyloidosis treatment have found that large dose intravenous chemotherapy followed by stem cell replacement, or rescue, is an effective treatment in many patients. Abnormal bone marrow cells are killed through high dose chemotherapy and the patient's own extracted blood stem cells are replaced in order to improve the recovery process.

I am part of a clinical trial and have gone through this procedure twice.

The high dose chemotherapy and stem cell rescue and other new drugs have increased the remittance and long term survival rate dramatically. However, most patients with these diseases still die from them.

RESEARCH, DIAGNOSIS AND TREATMENT

Research needs to be done to develop targeted treatments that will specifically attack the amyloid protein produced in the bone marrow. Additional funding for research and equipment is needed to accomplish this task. Only through more research is there hope of further increasing the survival rate and finding treatments to help more patients.

Timely diagnosis is also of great concern. Although I was diagnosed at a very early stage of the disease, many people are diagnosed after the point that they are physically able to undertake treatment.

Early treatment is the key to success. More needs to be done in this area to alert health professionals to identify this disease.

CURRENT INITIATIVES

Through the leadership of this Committee and the further involvement of the U. S. Government, a number of positive developments have occurred.

- The National Institutes of Health has substantially increased its interest in amyloidosis. The NIH participates in meetings and symposiums and works closely with organizations doing research and outreach on amyloidosis.
- There has been increased basic and clinical research at the Amyloid Treatment and Research Program: a model for the disease is under development; factors that cause protein misfolding are being identified; and new clinical trials are underway.
- Increased Federal funding for research, equipment and treatment has been another important element. This is essential to speed the pace of discovery for basic research.

REQUEST FOR FISCAL YEAR 2011

Mr. Chairman, I ask that the Committee take the following actions to help address this deadly disease.

- First, include language in your report identifying amyloidosis as an important concern and encouraging more research to find a cure.
- Second, continue to encourage the Centers for Disease Control and the National Institutes of Health to educate the American public and medical profession on the need to diagnose this disease at an early stage.

- Third, provide fiscal year 2011 funds within the Department of Health and Human Services for equipment and related assistance for the Amyloid Treatment and Research Program at the Boston University School of Medicine and the Boston Medical Center to assist in methods for treating and curing this tragic disease.

The United States Congress and the Executive branch working together are essential to finding a cure for and alerting people to this terrible disease

I ask for your support in helping me turn what has been my life-threatening experience into hope for others.

Thank you for your consideration.

Public Witness Testimony of Jill Kagan
Chair, National Respite Coalition
Policy Division of the ARCH National Respite Network, Washington, DC
jbkagan@verizon.net, 703-256-2084
For the House Subcommittee on Labor, HHS and Education Appropriations
April 12, 2010

Mr. Chairman, I am Jill Kagan, Chair of the ARCH National Respite Coalition, a network of respite providers, family caregivers, state and local agencies and organizations across the United States who support respite. Twenty-five state respite coalitions, including the Wisconsin Respite Care Association and the Kansas Lifespan Respite Coalition, are also affiliated with the NRC. This statement is presented on behalf of these organizations, as well as the members of the Lifespan Respite Task Force, a coalition of over 80 national and 100 state and local groups who supported the passage of the Lifespan Respite Care Act (P.L. 109-442). Together, we are requesting that the Subcommittee include funding for the Lifespan Respite Care Program administered by the US Administration on Aging in the FY 2011 Labor, HHS, and Education Appropriations bill at its modest authorized level of \$94.8 million. This will enable:

- State replication of best practices in Lifespan Respite systems to allow all family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today;
- Improvement in the quality of respite services currently available;
- Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

We join the 37 House Members, including the Chairman and Subcommittee Chairman of the program's authorizing committees and five other Committee and Subcommittee Chairmen, who, along with Rep. Langevin (D-RI), recently sent a letter to the Subcommittee urging full funding for Lifespan Respite in FY 2011.

Who Needs Respite?

In 2009, a national survey found that over 65 million family caregivers are providing care to individuals of any age with disabilities or chronic conditions (Caregiving in the U.S. 2009. Bethesda, MD: National Alliance for Caregiving and Washington, DC: AARP, 2009). It has been estimated that family caregivers provide \$375 billion in uncompensated care, an amount almost as high as Medicare spending (\$432 billion in 2007) and more than total spending for Medicaid, including both federal and state contributions and both medical and long-term care (\$311 billion in 2005) (Gibson and Hauser, 2008).

While the aging population is growing rapidly, increasing the need for family caregiver support for this age group, the **majority** of family caregivers are caring for someone **under age 75 (56%)**; 28% of family caregivers care for someone between the ages of 50-75, and 28% are caring for someone under age 50, including children (NAC and AARP, 2009). Family caregiving is not just an aging issue, but also a lifespan issue for the majority of the nation's families.

Compound this picture with the growing number of caregivers known as the "sandwich generation" caring for young children as well as an aging family member. It is estimated that between 20 and 40 percent of caregivers have children under the age of 18 to care for in addition

to a parent or other relative with a disability. And in the US, 6.7 million children, with and without disabilities, are in the primary custody of an aging grandparent or other relative.

Families of the wounded warriors – those military personnel returning from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions – are at risk for limited access to respite.

Together, these family caregivers provide an estimated 80% of all long-term care in the U.S. This percentage will only rise in the coming decades with an expected increase in the number of chronically ill veterans returning from war, greater life expectancies of individuals with Down's Syndrome and other disabling and chronic conditions, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

What is Respite Need?

State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers (Evercare and NAC, 2006). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the nation's family caregivers. The 2009 NAC/AARP survey of caregivers found that a majority (51%) have medium or high levels of burden of care, measured by the number of activities of daily living with which they provide assistance, and 31% of all family caregivers were identified as "highly stressed". Half of all family caregivers (53%) say that their caregiving takes time away from family and friends. Of those who sacrificed this time, 47% feel high emotional stress. Moreover, the 2009 survey found that despite the fact that among the most frequently reported unmet needs of family caregivers were "finding time for myself" (32%), "managing emotional and physical stress" (34%), and "balancing work and family responsibilities" (27%), only 11% of caregivers of adults 18+ use respite. This represents an increase from 5% in 2004, but still far less than the percentage who could benefit from respite. Of six proposed national policies or programs that could help caregivers, 3 in 10 selected respite as the preferred service (NAC and AARP, 2009). According to another survey in 2006, the percentage of family caregivers able to use respite in rural areas was only 4% (Easter Seals and NAC, 2006). In a study of a nationally representative profile of noninstitutionalized children ages 0-17 who were receiving support from the Supplemental Security Income (SSI) program because of a disability, only 8% reported using respite care but three quarters of families had unmet respite needs (Rupp, K. et al, 2005-2006).

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about how to find or choose a provider. Even when respite is an allowable funded service, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need.

Twenty of 35 state-sponsored respite programs surveyed in 1991 reported that they were unable to meet the demand for respite services. The 25 state coalitions and other National Respite Network members confirm that long waiting lists or turning away of clients because of lack of resources is still the norm. A study conducted by the Family Caregiver Alliance identified 150 family caregiver support programs in all 50 states and Washington, DC funded with state-only or state/federal dollars. Most of the funding comes through the federal National Family Caregiver Support Program. As a result, programs are administered by local area agencies on aging, primarily serve the aging, and provide only limited respite, if at all. Only about one-third of the 150 identified programs serve caregivers who provide care to adults age 18-60 who must meet stringent eligibility criteria. As the report concluded, "State program

administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the states.”

While most families take great joy in helping their family members to live at home, it has been well documented that family caregivers experience physical and emotional problems directly related to their caregiving responsibilities. Three-fifths of family caregivers age 19-64 surveyed recently by the Commonwealth Fund reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non-caregivers (Ho, Collins, Davis and Doty, 2005). A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age (Schulz and Beach, December 1999).

Supports that would ease their burden, most importantly respite, are too often out of reach or completely unavailable. Even the simple things we take for granted, like getting enough rest or going shopping, become rare and precious events. One Massachusetts mother of a seriously ill child spoke to the demands of constant caregiving: "I recall begging for some type of in-home support...It was during this period when I fell asleep twice while driving on the Massachusetts Turnpike on the way to appointments at Children's Hospital. The lack of respite...put our lives and the lives of everyone driving near me at risk."

Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services for which they once were eligible. A mother of a 12-year-old with autism was denied additional respite by her state DD (Developmental Disability) agency because she was not a single mother, was not at poverty level, was not exhibiting any emotional or physical conditions herself, and had only one child with a disability. As she told us, "Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service."

For the millions of families of children with disabilities, respite has been an actual lifesaver. However, for many of these families, their children will age out of the system when they turn 21 and they will lose many of the services, such as respite, that they currently receive. In fact, 46% of U.S. state units on aging identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities. An Alabama mom of a 19-year-old-daughter with multiple disabilities who requires constant care recently told us about her fears at a respite summit in Alabama, "My daughter Casey has cerebral palsy, she does not communicate, she is incontinent, she eats a pureed diet, utilizes a wheelchair, is unable to bathe or dress herself. At 5'5" and 87 pounds, I carry her from her bedroom to the bathroom to bathe her, and back again to dress her. Without respite, I do not think I could continue to provide the necessary long-term care that is required for my daughter. As I age, I wonder how much longer I will be able to maintain my daily ritual as my daughter's primary caregiver."

Disparate and inadequate funding streams exist for respite in many states. But even under the Medicaid program, respite is allowable only through state waivers for home and community-based care. Under the waivers, respite services are capped and limited to narrow eligibility categories. Long waiting lists are the norm.

Respite may not exist at all in some states for adult children with disabilities still living at home, or individuals under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions. In Tennessee, a young woman in her twenties gave up school, career and a relationship to move in and take care of her 53 year-old mom with MS when her dad left because of the strain of caregiving. She went for years providing constant care to her mom with almost no support. Now 31, she wrote, "And I was

young – I still am – and I have the energy, but – it starts to weigh. Because we’ve been able to have respite care, it has made all the difference.”

Respite Benefits Families and is Cost Saving

Respite has been shown to be a most effective way to improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A recent report from the US Dept of Health and Human Services prepared by the Urban Institute found that higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry. Reducing key stresses on caregivers, such as physical strain and financial hardship, through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007)

The budgetary benefits that accrue because of respite are just as compelling. Delaying a nursing home placement for just one individual with Alzheimer’s or other chronic condition for several months can save thousands of dollars. In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child’s disability and their parents missing more work hours than other employees. It was also found that the lack of available respite appeared to interfere with parents accepting job opportunities. (Abelson, A.G., 1999)

Moreover, data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (FY 1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999). A Massachusetts social services program designed to provide cost-effective family-centered respite care for children with complex medical needs found that for families participating for more than one year, the number of hospitalizations decreased by 75%, physician visits decreased by 64%, and antibiotics use decreased by 71% (Mausner, S., 1995).

In the private sector, the Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers. (MetLife and National Alliance for Caregiving, 2006). A more recent study from the National Alliance on Caregiving and Evercare demonstrated that the economic downturn has had a particularly harsh effect on family caregivers. Of the six in ten caregivers who are employed, 50% of them are less comfortable during the economic downturn with taking time off from work to care for a family member or friend. A similar percentage (51%) says the economic downturn has increased the amount of stress they feel about being able to care for their relative or friend. Respite for working family caregivers could help improve job performance and employers could potentially save billions.

Lifespan Respite Care Program Will Help

The Lifespan Respite Care Act is based on the success of statewide Lifespan Respite programs in Oregon, Nebraska, Wisconsin and Oklahoma. Arizona and Texas both recently passed state legislation to establish Lifespan Respite Programs, but Arizona’s program was cut due to state budget shortfalls. Twelve states, including AZ, began implementation in 2009 with the first wave of federal Lifespan Respite funding.

Lifespan Respite, which is a coordinated system of community-based respite services, helps states use limited resources across age and disability groups more effectively, instead of

each separate state agency or community-based organization being forced to reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and savings used to fund new respite services for families who may not qualify for existing federal or state programs. For the growing number of veterans returning home with TBI or other polytrauma, the shortage of staff qualified to provide respite to this population is especially critical. Lifespan Respite systems can make all the difference by ameliorating special barriers for this population

The first state Lifespan Respite programs in OR, NE, WI and OK provide best practices on which to build a national respite policy. The programs have been recognized by the National Conference of State Legislatures, which recommended the Nebraska program as a model for state solutions to community-based long-term care, the National Governors Association and the President's Committee for People with Intellectual Disabilities. The White House Conference on Aging recommended enactment of the Lifespan Respite Care Act to Congress.

The purpose of the law is to expand and enhance respite services, improve coordination, and improve respite access and quality. Under a competitive grant program, states would be required to establish state and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services. Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs.

The federal Lifespan Respite program is administered by the U.S. Administration on Aging, Department of Health and Human Services (HHS). AoA provides competitive grants to state agencies in concert with Aging and Disability Resource Centers working in collaboration with state respite coalitions or other state respite organizations. The program was authorized at \$53.3 million in FY 09 rising to \$95 million in FY 2011. Congress appropriated \$2.5 million in FY09 and again in FY 2010. In FY 09, twelve states received 36-month \$200,000 grants to implement Lifespan Respite. In these states, that represents less than \$.18 per caregiver.

The Administration recommended \$5 million for Lifespan Respite as part of its Middle Class Initiative. We are heartened to see that support for family caregiving is recognized as a critical component of a typical family's economic and social well-being. However, the focus of the Administration's request was on support for family caregivers of the aging population. While this is an issue of growing concern, we must not neglect that fact that at least half of the nation's family caregivers are caring for someone with MS, ALS, traumatic brain or spinal cord injury, mental health conditions, developmental disabilities or cancer who are under the age of 60 and \$5 million will not address their need for respite. This is also the population most likely to be ineligible for any existing state or federal respite resources.

No other federal program mandates respite as its sole focus. No other federal program would help ensure respite quality or choice, and no current federal program allows funds for respite start-up, training or coordination or to address basic accessibility and affordability issues for families. We urge you to include \$94.8 million in the FY 11 Labor, HHS, Education appropriations bill so that Lifespan Respite Programs can be replicated in the states and more families, with access to respite, will be able to continue to play the significant role in long-term care that they are fulfilling today.

Complete references available upon request. Prepared by Jill Kagan, Chair, National Respite Coalition, 4016 Oxford Street, Annandale, VA, 22003; 703-256-2084; jbkagan@verizon.net; www.archrespite.org.

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**Testimony of the Arthritis Foundation
Submitted to the Senate Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
April 12, 2010**

The Arthritis Foundation greatly appreciates the opportunity to submit testimony in support of increased funding for arthritis prevention at the Centers for Disease Control and Prevention (CDC); additional investment in arthritis research at the National Institutes of Health (NIH); and funding for the Health Resources and Services Administration (HRSA) to commence a loan repayment program for pediatric specialists.

Arthritis is a term used to describe more than 100 different conditions that affect joints as well as other parts of the body. Arthritis is one of the most prevalent chronic health problems and the most common cause of disability in the United States. 46 million people (1 in 5 adults) and almost 300,000 children live with the pain of arthritis every day. The medical and societal impact of arthritis in the United States is staggering at \$128 billion, including \$81 billion in direct costs for physician visits and surgical interventions and \$47 billion in indirect costs for missed work days. Counter to public perception, two-thirds of the people with doctor-diagnosed arthritis are under the age of 65.

By the year 2030, an estimated 67 million or 25% of the projected adult population will have arthritis. Furthermore, arthritis limits the ability of people to effectively manage other chronic diseases. More than 57% of adults with heart disease and more than 52% of adults with diabetes also have arthritis. The Arthritis Foundation strongly believes that in order to prevent or delay arthritis from disabling people and diminishing their quality of life that a significant investment in prevention and intervention strategies is essential. Research shows that the pain and disability of arthritis *can* be decreased through early diagnosis and appropriate management, including evidence based self-management activities such as weight control and physical activity. The Arthritis Foundation's Self-Help Program, a group education program, has been proven to reduce arthritis pain by 20% and physician visits by 40%. These interventions are recognized by the CDC to reduce the pain of arthritis and importantly reduce health care expenditures through a reduction in physician visits.

Centers for Disease Control and Prevention

During the past year, the Centers for Disease Control and Prevention has partnered with the Arthritis Foundation and more than 50 organizations to create a ***National Public Health Agenda for Osteoarthritis***. The Agenda states the need to increase availability of evidence-based intervention strategies; increase public health attention for prevention and disease management; and increase research to better understand disease risk factors and other effective disease management strategies.

With CDC funding, twelve state health departments in partnership with other state organizations have successfully increased public awareness of the burden of arthritis and increased the availability of four main interventions. First, self-management education (as described above) is proven to improve the quality of life and health care for people with arthritis and should be expanded to people with symptomatic arthritis. Second, physical activity is the best medicine to fight arthritis pain. The promotion of low-impact aerobic physical activity and muscle strengthening exercises for weight loss and to provide joint support is key. Losing just one pound of weight reduces four pounds of pressure off each knee. Third, preventing joint injuries through existing policies and interventions which have been shown to reduce arthritis related joint injuries. Finally, promoting weight management and healthy nutrition will facilitate the prevention and treatment of arthritis. Now, is the time to make a significant investment to sustain and improve the reach of these proven interventions.

Currently, the CDC's arthritis program receives \$13 million in annual funding and about half of that amount is distributed via competitive grant to 12 states. An additional investment of \$10 million would fund 12-14 new states and enable evidence-based prevention programs to reach many more Americans through innovative delivery approaches. **The Arthritis Foundation strongly recommends that Congress invest an additional \$10 million (total of \$23 million) in the CDC's arthritis program in Fiscal Year 2011 to expand proven prevention and treatment strategies and fund up to 14 new states.**

National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases

While new treatment options are available which greatly improve the quality of life for people living with arthritis, the ultimate goal is to find a cure. The Arthritis Foundation firmly believes research holds the key to tomorrow's advances and provides hope for a future free from arthritis pain. As the largest non-profit contributor to arthritis research, the Arthritis Foundation fills a vital role in the big picture of arthritis research. Our research program complements government and industry-based arthritis research by focusing on training new investigators and pursuing innovative strategies for preventing, controlling and curing arthritis. By supporting researchers in the early stages of their careers, the Arthritis Foundation makes important initial discoveries possible that lead to ultimate breakthrough results.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases. Research opportunities at NIAMS are being curtailed due to the stagnating and in some cases declining numbers of new grants being awarded for specific diseases. The training of new investigators has unnecessarily slowed down and contributed to a crisis in the research community where new investigators have begun to leave biomedical research careers in pursuit of other more successful endeavors.

The Arthritis Foundation is dedicated to finding a cure for arthritis. However, the investment in NIH research is absolutely crucial to realize this dream. With continued and increased

investment in research, the Arthritis Foundation believes a cure is on the horizon. **To support research that will lead to improved treatments and a potential cure for arthritis, the Arthritis Foundation urges Congress to provide \$603.8 million, a 12% increase, for the National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases.**

Health Resources and Services Administration

Juvenile arthritis is the leading cause of acquired disability in children and is the sixth most common childhood disease. Sustaining the field of pediatric rheumatology is essential to the care of the almost 300,000 children under the age of 18 living with a form of juvenile arthritis. Children who are diagnosed with juvenile arthritis will live with this chronic and potentially disabling disease for their entire life. Therefore, it is imperative that children are diagnosed quickly and start treatment before significant irreversible joint damage is done. However, it is a challenge to first find a pediatric rheumatologist, as nine states do not have a single one, and then to have a timely appointment as many states have only one or two to see thousands of patients. Pediatric rheumatology is one of the smallest pediatric subspecialties with less than 200 pediatric rheumatologists actively practicing in the United States. A report to Congress in 2007 stated there was a 75% shortage of pediatric rheumatologists and recommended loan repayment program to help address the workforce issue.

The recent passage of the *Patient Protection and Affordable Care Act* authorizes the Health Resources and Services Administration to commence a loan repayment program for pediatric specialists and authorizes Congress to appropriate \$30 million for this program. A percentage of this funding should be allocated for pediatric rheumatology. **The Arthritis Foundation strongly recommends funding this program immediately at the \$30 million level to help increase the pediatric rheumatology workforce.**

The Arthritis Foundation appreciates the opportunity to submit our recommendations to Congress on behalf of the 46 million people with arthritis. The mission of the Arthritis Foundation is the prevention, control, and cure of arthritis. The Arthritis Foundation urges Congress to focus federal investment through a \$23 million appropriation for arthritis prevention at CDC; a \$30 million appropriation to help control juvenile arthritis; and a 12% increase toward a cure in arthritis research at the NIH. Each part of the equation—prevention, control, and cure—are an essential part to a future world free of arthritis pain and disability.

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**Testimony of
The Association for Professionals in Infection Control and Epidemiology (APIC)
to the House of Representatives Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
on Fiscal Year 2011 Appropriations for the
U.S. Department of Health and Human Services (HHS)
April 16, 2010**

The Association for Professionals in Infection Control and Epidemiology (APIC) thanks you for this opportunity to submit testimony and greatly appreciates this subcommittee's leadership in providing the necessary funding for the federal government to have a leadership role in the effort to eliminate healthcare-associated infections (HAIs).

APIC's mission is to improve health and patient safety by reducing the risk of healthcare-associated infections and related adverse outcomes. The organization's more than 13,000 members, known as infection preventionists, direct infection prevention programs that save lives and improve the bottom line for hospitals and other healthcare facilities throughout the United States and around the globe. Our association strives to promote a culture within healthcare institutions where all members of the healthcare team fully embrace the elimination of HAIs. We advance these efforts through education, research, collaboration, practice guidance, public policy and credentialing.

HAIs are among the leading causes of preventable death in the United States, accounting for an estimated 1.7 million infections and 99,000 associated deaths in 2002. In addition to the substantial human suffering caused by HAIs, these infections contribute \$28 billion to \$33 billion in excess healthcare costs each year.

We are greatly appreciative of funding provided in the FY2010 Consolidated Appropriations Act to resource HAI reduction efforts. In particular, we support the \$5 million appropriation for the HHS Office of the Secretary to coordinate and integrate HAI-related activities across the Department, \$136 million for the Centers for Disease Control and Prevention's (CDC) emerging infectious diseases portfolio for expanded surveillance, public health research and prevention activities, \$15 million to expand the CDC National Healthcare Safety Network (NHSN) and finally, \$34 million for the Agency for Healthcare Research and Quality's (AHRQ) MRSA Collaborative Research Initiative and for implementing evidence-based HAI prevention training nationwide.

In Fiscal Year 2011, we ask that you support the CDC Coalition's \$8.8 billion for CDC's "core programs." CDC serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. From pandemic flu preparedness and prevention activities to West Nile virus to smallpox to SARS, the Centers for Disease Control and Prevention is the nation's -- and the world's -- expert resource and response center, coordinating communications and action and serving as the laboratory reference center. APIC members rely on CDC for accurate information and direction in a crisis or outbreak. We ask that you provide \$2.3 billion for the CDC's Infectious Diseases programs.

Because our members are on the front line in healthcare facilities, bringing their expertise in infection prevention to the patient's bedside, there are so many areas within the CDC budget that we could highlight. Allow us to outline some of the areas of greatest concern to our membership. We support the Administration's FY 2011 request for \$27 million to expand NHSN to approximately 2,500 new hospitals. Currently, 21 states require hospitals to report HAIs using NHSN. However, CDC supports more than 2,300 participating hospitals in NHSN in all 50 states. This surveillance system plays an important role in improving patient safety at the local and federal levels. NHSN's data analysis function helps our members analyze facility-specific data and compare rates to national aggregate metrics. It also allows CDC to estimate and characterize the current burden of HAIs in the United States. Every step taken to create interoperable data systems in which our members can input HAI data and have it go directly to NHSN is a step toward freeing our members to do more hands-on infection prevention activities.

We also appreciate the Administration's proposal of \$155.9 million for emerging infectious diseases in FY 2011 and ask that you increase funding for this purpose to \$200 million to allow CDC to work with partners at the state and local level to detect and respond to this important public health threat.

In addition, we support the \$10 million budget request for the new Health Prevention Corps. We appreciate the importance of targeting disciplines with existing shortages with a workforce program designed to recruit talented new individuals for state and local health departments.

APIC is concerned that the Administration's proposed budget would cut the Antimicrobial Resistance budget by \$8.6 million, just over 50 percent. We agree with the agency's congressional justification that this is "one of the world's most pressing public health problems" and ask that you increase funding for CDC antimicrobial resistance activities in FY2011 to \$40 million.

In addition, we support the \$34 million in the Administration's FY 2011 budget to build upon AHRQ efforts -- now in all 50 states, the District of Columbia and Puerto Rico -- to reduce bloodstream infections in intensive care units (ICUs) through implementation of a safety compliance checklist and providing staff with evidence-based practices. We support these efforts and AHRQ's plans to reach out to the CDC to identify and design projects to reduce the incidence of HAIs in other infection sites using evidence-based practices.

Further, APIC supports the Administration's request to build upon American Recovery and Reinvestment Act (ARRA) efforts by supporting use of the HAI survey tool developed jointly by

CDC and the Centers for Medicare and Medicaid Services (CMS) with ARRA funds. The Administration's FY2011 request under Survey and Certification would increase survey frequencies at ambulatory surgery centers (ASCs) to every four years. Due to the increasing number of surgeries performed in outpatient settings, and the need to ensure that basic infection prevention practices are followed, APIC supports efforts to increase the use of this survey tool.

Finally, we support the Administration's \$5 million request for HAI activities to support continued efforts of the HHS Action Plan to Prevent Healthcare-Associated Infections (HAI Action Plan). This funding will allow HHS to continue current efforts and expand upon a national media campaign, utilize social media tools, develop a single comprehensive website for HAI information, and evaluate the media campaign and original Action Plan and assess whether it is achieving its intended goals.

We believe the development of the HAI Action Plan and the funding to support these activities has been an essential tool in the effort to build support for a coordinated federal message on preventing infections. Additionally, we feel very strongly that the CDC has the necessary expertise to define appropriate metrics through which the HAI Action Plan can best measure its efforts.

APIC strongly believes that to move toward our goal of HAI elimination, there needs to be a concerted effort to fund research into the knowledge gaps outlined in the HAI Action Plan, with an eye toward the science of implementation.

This subcommittee has taken essential steps in using stimulus funds to build the necessary infrastructure within states to address HAI reduction. Your leadership has also put resources into improving surveillance efforts and scaling-up proven HAI prevention approaches. However, while resources have encouraged states to plan for HAI prevention efforts, APIC's 2009 Economic Survey of our membership indicates that infection prevention budgets within healthcare facilities have been hard hit, particularly in the area of education.

Three-quarters of our members who reported that their budgets were cut in our recent survey have experienced decreases for the education that trains healthcare workers in preventing HAI transmission. Half saw reductions in overall budgets for infection prevention, including money for technology, staff, education, products equipment and updated resources. Nearly 40 percent had layoffs or reduced hours. While we fully support your effort to put infrastructure in place in states to promote HAI reduction efforts and believe that was a very wise use of one-time stimulus funding, we need to make clear that our membership would be hard-pressed to scale up HAI reduction efforts while their budgets are facing these kinds of decreases.

We thank you for the opportunity to submit testimony and greatly appreciate this subcommittee's leadership in providing the necessary funding for the federal government to have a leadership role in the effort to eliminate HAIs.

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TESTIMONY on the FY 2011 BUDGET of the
NATIONAL INSTITUTES OF HEALTH
before the
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

THE HONORABLE DAVID OBEY, CHAIR
April 16, 2010

SUMMARY OF RECOMMENDATIONS

- As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$35 billion for NIH in FY 2011.
- APS requests Committee support for behavioral and social science research and training as a core priority at NIH in order to: better meet the Nation's health needs, many of which are behavioral in nature; realize the exciting scientific opportunities in behavioral and social science research, and; accommodate the changing nature of science, in which new fields and new frontiers of inquiry are rapidly emerging.
- Given the critical role of basic behavioral science research and training in addressing many of the Nation's most pressing public health needs, we ask the Committee to ensure that NIH leadership sustains its cross-NIH basic behavioral research funding initiative, the Basic Behavioral and Social Science Opportunity Network (OppNet), and coordinates with all Institutes and Centers to provide support for basic behavioral science research.
- APS encourages the Committee to support behavioral science priorities at individual institutes. Examples are provided in this testimony to illustrate the exciting and important behavioral and social science work being supported at NIH.

Mr. Chairman, Members of the Committee: My name is Dr. Amy Pollick, and I am speaking on behalf of the Association for Psychological Science. Thank you for the opportunity to provide this statement on the FY 2011 appropriations for the National Institutes of Health. As our organization's name indicates, APS is dedicated to all areas of scientific psychology, in research, application, teaching, and the improvement of human welfare. Our 22,000 members are scientists and educators at the Nation's universities and colleges, conducting NIH-supported basic and applied, theoretical and clinical research. They look at such things as: the connections between emotion, stress, and biology and the impact of stress on health; they look at how children grow, learn, and develop; they use brain imaging to explore thinking and memory and other aspects of cognition; they develop ways to manage debilitating chronic conditions such as diabetes and arthritis as well as depression and other mental disorders; they look at how genes and the environment

influence behavioral traits such as aggression and anxiety; and they address the behavioral aspects of smoking and drug and alcohol abuse.

As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$35 billion for NIH in FY 2011, an increase of 12.6% over the FY 2010 appropriations level. This increase would halt the erosion of the Nation's public health research enterprise, and help restore momentum to our efforts to improve the health and quality of life of all Americans.

Within the NIH budget, APS is particularly focused on behavioral and social science research and the central role of behavior in health. The remainder of my testimony concerns the status of those areas of research at NIH.

HEALTH AND BEHAVIOR: THE CRITICAL ROLE OF BASIC AND APPLIED PSYCHOLOGICAL RESEARCH

Behavior is a central part of health. Many leading health conditions – such as heart disease; stroke; lung disease and certain cancers; obesity; AIDS; suicide; teen pregnancy; drug abuse and addiction; depression and other mental illnesses; neurological disorders; alcoholism; violence; injuries and accidents – originate in behavior and can be prevented or controlled through behavior.

As just one example: stress is something we all feel in our daily lives, and we now have a growing body of research that illustrates the direct link between stress and health problems:

- chronic stress accelerates not only the size but also the strength of cancer tumors;
- chronic stressors weaken the immune system to the point where the heart is damaged, paving the way for cardiac disease;
- children who are genetically vulnerable to anxiety and who are raised by stressed parents are more likely to experience greater levels of anxiety and stress later in life;
- animal research has shown that stress interferes with working memory; and
- stressful interactions may contribute to systemic inflammation in older adults, which in turn extends negative emotion and pain over time.

None of the conditions or diseases described above can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating, and preventing them. Just as there exists a layered understanding, from basic to applied, of how molecules affect brain cancer, there is a similar spectrum for behavioral research. For example, before you address how to change attitudes and behaviors around AIDS, you need to know how attitudes develop and change in the first place. Or, to design targeted therapies for bipolar disorder, you need to know how to understand how circadian rhythms work as disruptions in sleeping patterns have been shown to worsen symptoms in bipolar patients.

NIH's New Commitment to Basic Behavioral Science Research Should Be Made Permanent

Broadly defined, behavioral research explores and explains the psychological, physiological, and environmental mechanisms involved in functions such as memory, learning, emotion, language, perception, personality, motivation, social attachments, and attitudes. Within this, *basic* behavioral research aims to understand the fundamental nature of these processes in their own right, which provides the foundation for *applied* behavioral research that connects this knowledge to real-world concerns such as disease, health, and life stages. Thanks in large part to the leadership of this Committee and your counterparts in the Senate, NIH has launched a new initiative that supports and expands new basic behavioral research throughout NIH. In November 2009, NIH leadership launched the Basic Behavioral and Social Science Opportunity Network (OppNet), and has already released several funding opportunities. OppNet is currently organizing its strategic plan to prioritize research areas it will fund over the next four years. This plan

should include, at the very least, the following areas of research that will be critical to its success and more importantly, critical for the NIH to best take advantage of what this field has to offer:

- identifying the dimensions of the environment that create, moderate, and reverse risks for mental and physical health disorders;
- a rigorous understanding of emotions, their regulation, and functions;
- development of multiple methods of behavioral measurement;
- the role of emotions and environmental factors in behavior change;
- animal models of behavior that enrich our understanding of human mechanisms;
- interpersonal interactions across the lifespan and across social, economic, and cultural contexts; and
- individual processes underlying personality, self, and identity.

While we are greatly encouraged by the launch of OppNet, it is slated to end in 2014. That, combined with the lack of a permanent organizational structure for basic behavioral research at NIH, creates enormous uncertainty for an enterprise that by nature inherently requires a longer-term, stable commitment.

APS respectfully asks the Committee to:

- (1) ensure that NIH adequately supports and sustains a strong, permanent program of basic behavioral science research and training as a critical element in improving the health and welfare of all Americans, and
- (2) ensure that behavioral research is a priority at NIH both by providing maximum funding for those institutes where behavioral science is a core activity and by encouraging NIH to advance a model of health that includes behavior in its scientific priorities.

Psychological Clinical Science Training and Public Health

One in 4 adults and one in 5 children in the U.S. have a diagnosable mental disorder that impairs normal functioning, and mental illness accounts for over 15% of the burden of disease in major nations; the economic burden associated with mental illness exceeds that of all forms of cancer combined. The costs associated with mental illness are staggering: \$69 billion was spent on mental health services in the U.S. alone in 1996. This is over 7% of our total health spending. For these reasons, it is critical that our understanding of, diagnosis, treatment, and prevention of mental illness reflects the very best and most modern science possible.

Unfortunately, the vast majority of clinical psychologists are currently being trained outside of the major research universities and hospitals. Even in the best of these training programs, students receive little or no direct contact with cutting-edge research. In many of these programs there is even an anti-science bias; students in these programs are being trained to diagnose and treat mental illness using methods that have no scientific support or, even worse, that have been shown to be of little or no value. To combat this problem, a group of the top 50 clinical psychology programs in the U.S. formed the Academy for Psychological Clinical Science, an organization committed to reaffirming the critical importance of science in clinical psychology training. The Academy recently established an independent accreditation system to insure that clinical psychology training programs meet the highest scientific standards, which will be critical for re-establishing the scientific foundation of clinical psychology.

Individuals with mental illness and their families will know that practitioners who graduate from these programs will be delivering treatments that incorporate state-of-the-art scientific advances and that have passed the most critical scientific tests of their efficacy. Those communities and organizations wishing to provide state-of-the-art, scientifically-based mental health services will know where to seek consultation

and find the very best personnel. And finally, this new accreditation system will increase the supply of highly-skilled scientists who will continue to fight the good fight against the ravages of mental illness.

The National Institute of Mental Health's (NIMH) mission includes the assurance that the science-based interventions its researchers generate can be used by patients, families, health care providers, and the wider community involved in mental health care. Most of the institutions that will be accredited under the new system (called the Psychological Clinical Science Accreditation System) include NIMH-funded researchers, and NIMH has already begun to support the new system in the spirit of advancing scientifically-sound treatments that its research helped develop. APS asks the Committee to support the new accreditation system for psychological clinical science training programs in order to reduce the burden of mental illness on individuals, families, communities, and society, through the use of empirically-validated treatments by qualified practitioners.

BEHAVIORAL SCIENCE AT KEY INSTITUTES

In the remainder of my testimony, I would like to highlight examples of cutting-edge behavioral science research being supported by individual institutes.

National Cancer Institute (NCI): NCI is at the forefront of supporting behavioral science in the spirit of advancing the Nation's effort to prevent cancer. The Behavioral Research Program continues to invest in research on the development and dissemination of interventions in areas such as tobacco use, dietary behavior, sun protection, and decision-making. For example, knowledge about basic psychological mechanisms can be brought to bear on warnings about risky behavior, with a particular focus on tobacco use. The recently enacted FDA regulation of tobacco products is a landmark opportunity for tobacco control, and it presents a complementary invitation for psychological science to revolutionize the study of warning labels and risky behavior. Specifically, recent research on graphic warning labels for cigarettes indicates that specific types of images can improve understanding of the consequences of smoking, and encourage motivations to quit smoking. APS asks the Committee to support NCI's behavioral science research and training initiatives and to encourage other Institutes to use these programs as models.

National Institute on Aging (NIA): NIA's Division of Behavioral and Social Research has one of the strongest psychological science portfolios in all of NIH, and is supporting wide-ranging and innovative work. For example, older individuals face important and often complex decisions about retirement, income distribution, insurance, and other financial and health-related matters, and the normal aging process alters many of the psychological capacities and neural systems that come into play when making these decisions. Researchers are now looking at how healthy aging influences the psychological and neural bases of economic choice, and hope to speed along the development of interventions that remediate problems with decision-making in the elderly, resulting in benefits to public health. NIA's commitment to cutting-edge behavioral science is further illustrated by the Institute's leadership role in NIH's new Common Fund initiative on the Science of Behavior Change. APS asks the Committee to support NIA's behavioral science research efforts and to increase NIA's budget in proportion to the overall increase at NIH in order to continue its high quality research to improve the health and wellbeing of Americans across the lifespan.

Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD): NICHD is to be commended for supporting a broad spectrum of behavioral research, particularly as it relates to real-world problems. Let me give you one example, centering on the effects of socioeconomic adversity on children's brain development. Researchers are beginning to clarify the relationship among socioeconomic status (SES), early life experience, and learning in adolescents. We know that learning ability is positively correlated with SES, and recent research suggests that the effects of childhood

experience on the development of certain parts of the brain may partially explain this. Researchers at the University of Pennsylvania are now learning about the nature and causes of the SES disparity in learning ability by examining its scope across different types of learning and different neural systems, and assessing its relation to early experience, including stress and parental nurturing. Thus, we are closer to understanding the crucial role played by learning in the academic, occupational, and personal lives of all Americans, and the prospect of preserving and fostering the learning ability in at-risk youth through the application of insights from the cognitive neuroscience of memory, stress, and early experience. APS asks the Committee to support NICHD's sustained behavioral science research portfolio and to encourage other Institutes to partner with NICHD to maximize the development of interventions in early stages of life that have invaluable benefits in adulthood.

National Institute on Deafness and Other Communication Disorders (NIDCD): NIDCD supports a vibrant and important portfolio of behavioral science research on voice, speech, and language. This research expands our understanding of the role of each hemisphere of the brain in communication and language, of early specialization of the brain, and of the recovery process following brain damage. This research will further our understanding of the neural bases of language disorders. More recently, scientists are also exploring the genetic bases of child language disorders, as well as characterizing the linguistic and cognitive deficits in children and adults with language disorders. For example, specific language impairment (SLI) is a communication disorder where acquisition and mastery of language is delayed in the absence of other problems such as mental retardation, hearing loss, or emotional disorders. It affects about seven percent of 5-6 year olds and tends to appear in families, suggesting a genetic component. However, until now, no specific genes have been linked to SLI. But new research is studying this link, and one gene, *KIAA0319*, appears to play a key role in SLI, and plays a supporting role in other learning disabilities such as dyslexia. This research is verifying that difficulties in reading and language may stem from the same molecular pathways in the brain. This and similar research programs are important as they offer valuable insight into the basis of the disorder and the associated academic problems encountered by many children with SLI. They are also likely to improve the classification, diagnosis, and treatment of other language, reading, and speech disorders. APS asks the Committee to support NIDCD's behavioral science research program and to increase NIDCD's budget in proportion to the overall increase at NIH in order to continue making significant advances in our understanding of and treatments for communication disorders in Americans of all ages.

It's not possible to highlight all of the worthy behavioral science research programs at NIH. In addition to those reviewed in this statement, many other institutes play a key role in the NIH behavioral science research enterprise. These include the National Institute of Mental Health, the National Institute on Alcohol Abuse and Alcoholism, the National Institute on Drug Abuse, the National Heart, Lung, and Blood Institute, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute on Neurological Diseases and Stroke, and the National Institute on Dental and Craniofacial Research. Behavioral science is a central part of the mission of these institutes, and their behavioral science programs deserve the Committee's strongest possible support.

This concludes my testimony. Again, thank you for the opportunity to discuss NIH appropriations for FY 2011 and specifically, the importance of behavioral science research in addressing the Nation's public health concerns. I would be pleased to answer any questions or provide additional information.

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[About ARVO appears on last page.]

April 16, 2010

ARVO Written Testimony in Support of Increased FY11 Funding for the National Institutes of Health (NIH) and the National Eye Institute (NEI)
[Submitted on behalf of the ARVO President, Nicholas A. Delamere, PhD]

House Committee on Appropriations Subcommittee on
Labor, Health & Human Services, Education, and Related Agencies

ARVO has two major requests:

- 1) **For Congress to fund NIH in FY11 at \$35 billion;**
- 2) **For Congress to make vision health a priority in the total funding of NIH by increasing NEI funding more than the President's proposed 2.5 percent increase for NEI.**

The requested increase in the total NIH budget is a \$3 billion increase over President Obama's proposed funding level of \$32 billion. We are also concerned that NEI funding has been less than the increase for NIH funding for all funding cycles since 2001. NEI has lost 20.1 percent loss in purchasing power* over the last 10 years, while NIH has lost 17.2 percent loss in purchasing power* over the last 10 years.

ARVO commends Congress for actions taken in FY09 and FY10 to fund NIH. This includes the \$10.4 billion for NIH funding in the American Recovery and Reinvestment Act (ARRA). We also applaud the fact that the 2011 NIH budget draft, requesting a 3.2% increase for NIH, keeps pace with inflation for the first time in 10 years. However, ARVO still has concerns about long-term, sustained and predictable funding for vision research at the NEI, which has lost approximately 3% more purchasing power* than NIH in the past decade, which is not in proportion to the fact that vision disorders are the fourth most prevalent disability in the US and the most frequent cause of disability in children.¹⁻⁴

ARVO also commends Congress for passing S. Res. 209 and H. Res. 366, which acknowledged NEI's 40th anniversary as a free-standing institute and designated 2010-2020 as the *Decade of Vision*, in which the majority of 78 million baby boomers will turn age 65 and face great risk of developing aging eye diseases. In a 2007 report, age-related eye diseases were estimated to cost \$1.4 billion.⁵ Costs to health care also add up when more individuals with vision impairment live in nursing homes than would be the case if they had normal vision.⁶ NEI-funded research

results in treatments and therapies that save vision, restore sight, reduce healthcare costs, maintain productivity, ensure financial independence, and enhance quality of life.

ARVO requests \$35 billion in NIH funding for FY11, especially to ensure that NEI can build upon the impressive record of basic and clinical collaborative research that meets NIH's top five priorities and has been funded through FY09-10 ARRA and regular appropriations.

NEI research addresses the top five NIH priorities, as identified by Dr. Collins: genomics, translational research, comparative effectiveness, global health, and empowering the biomedical enterprise.⁷ Such research also addresses the preemption, prediction, personalization (ex. gene therapy), and prevention of eye disease through basic, translational, epidemiological, and comparative effectiveness research. NEI continues to be a leader within NIH for elucidating the genetic basis of eye disease. NEI Director, Paul Sieving, MD, PhD has reported that one-quarter of all genes identified to date through collaborative efforts with the National Human Genome Research Institute (NHGRI) are associated with eye disease/visual impairment.

NEI received \$175 million of the \$10.4 billion in NIH ARRA funding. As a result, NEI's total funding levels in the FY2009-2010 timeframe were \$776 million and \$794.5 million, respectively. In FY2009, NEI made 333 ARRA-related awards, the majority of which reflect investigator-initiated research that funds new science or accelerates ongoing research, including ten Challenge Grants. Several examples of research, and the reasons why it is important, include:

- **Biomarker for Neovascular Age-related Macular Degeneration (AMD):**
 Researchers are utilizing a recently discovered biomarker to develop an early detection method to minimize vision loss. This marker identifies a risk factor (for abnormal growth of blood vessels into the retina), which causes 90 percent of the vision loss associated with AMD. Importance: 1.75 million people were living with AMD in 2000, and the number is estimated to reach 3 million by 2020.⁸ Without accounting for healthcare inflation, the most recent estimated of cost for AMD⁹ treatment times 3 million is (2.5-4.8 billion dollars) over 5 years.
- **Cellular Approach to Treating Diabetic Retinopathy (DR):**
 Researchers are developing a clinical treatment for diabetic retinopathy by using specially treated stem cells from the patient's own blood to repair damaged vessels in the eye. Importance: DR is increasing in younger Americans and the aging population. In a 2004 paper, the reported prevalence was 4.1 million Americans.¹⁰
- **Small Heat Shock Proteins as Therapeutic Agents in the Eye:**
 Researchers propose to develop new drugs to prevent or reverse blinding eye diseases, such as cataract (clouding of the lens), that are associated with the aggregation of proteins. Research will focus on the use of small "heat shock" proteins that facilitate the slow release and prolonged delivery of targeted macromolecules to degenerating cells of the eye. Importance: Delivering effective, long-lasting therapies through a

minimally invasive route into the eye may help to reduce cataracts, the leading cause of low vision among all Americans.¹¹

- **Identification of Genes and Proteins that Control Myopia Development:**
 Researchers propose to identify targets that will facilitate development of interventions to slow or prevent myopia (nearsightedness) development in children. Identifying an appropriate myopia prevention target can reduce the risk of blindness and reduce annual life-long eye care costs.
Importance: More than 25 percent of the US population has myopia, costing \$14 billion annually, from adolescence to adulthood (data from NEI-supported study on myopia).¹³
- **Comparison of Interventions for Retinopathy of Prematurity (ROP):**
 In animal studies, researchers will simulate Retinopathy of Prematurity—a blinding eye disease that affects premature infants—and then study novel treatments that involve modulating the metabolism of the retina’s rod photoreceptors. Importance: ROP affects 15,000 children a year, about 400-600 of whom progress to blindness, at an estimated lifetime cost for support and unpaid taxes of \$1 million each.¹⁴⁻¹⁵
- **The NEI Glaucoma Human genetics collaBORation, NEIGHBOR:**
 This research network, in which seven US teams will lead genetic studies of the disease, may lead to more effective diagnosis and treatment. Researchers were primarily funded through ARRA supplements. Importance: Glaucoma, a complex neurodegenerative disease that is the second leading cause of preventable blindness in the US, often has no symptoms until vision is lost.¹⁶
- **Comparative Effectiveness of Interventions for Primary Open Angle Glaucoma (POAG):**
 Researchers will evaluate existing data on the effectiveness of various treatment options for primary open angle glaucoma—many emerging from past NEI research. Importance: POAG is the most common form of the disease, which disproportionately affects African Americans and Latinos. It is estimated that 3.36 million individuals will have glaucoma by 2020.¹⁷ This number times the average cost of treatment,¹⁸ not accounting for inflation, is (2.1-8.4 billion dollars/year).

In addition to ARRA funding, the “regular” appropriations increases in FY2009-2010 enabled the NEI to continue to fund key research networks, such as the following:

- **The African Descent and Glaucoma Evaluation Study (ADAGES),** which is designed to identify factors accounting for differences in glaucoma onset and rate of progression between individuals of African and European descent. Importance: African Americans are more than three times as likely to develop visual impairment from glaucoma, compared to other ethnic groups.¹⁹
- **The Diabetic Research Clinical Research Network’s (DRCR)** initiation of new trials comparing the safety and efficacy of drug therapies as an alternative to laser treatment for diabetic macular edema and proliferative diabetic retinopathy. Importance: In 2007, an

estimated 23.6 million Americans were living with diabetes, and almost 1.6 million new cases were diagnosed per year. One out of twelve individuals with diabetes has diabetic retinopathy.²⁰

- **The Neuro-Ophthalmology Research Disease Investigator Consortium (NORDIC)**, which will lead multi-site observational and treatment trials, involving nearly 200 community and academic practitioners, to address the risks, diagnosis, and treatment of visual dysfunction due to increased intracranial pressure and thyroid eye disease. Importance: A broad spectrum of neuro-ophthalmic disorders collectively affects millions of people. Many are associated with other neurological disease processes and have not been adequately investigated because they are rare. NORDIC will address unanswered questions about risks, diagnosis, and treatment that could not be studied without a clinical research organization.²¹

The unprecedented level of FY2009-2010 vision research funding is moving our nation that much closer to the prevention of blindness and restoration of vision. With an overall NIH funding level of \$35 billion, which translates to an NEI funding level of \$794.5 million, the vision community can accelerate these efforts, thereby reducing healthcare costs, maintaining productivity, ensuring independence, and enhancing quality of life.

Summary

ARVO urges FY2011 NIH and NEI funding at \$35 billion and \$794.5 million, respectively.

References

Fully referenced version is available at (<http://bit.ly/8GTHH>)

*Calculations were based solely upon annual biomedical research and development price index and annual appropriated amounts.

About ARVO

ARVO is the world's largest international association of vision scientists (scientists who study diseases and disorders of the eye). About eighty percent of the United States members (>7,000 total) are supported by NIH grant funding. Vision science is a multi-disciplinary field, but the National Eye Institute is the only freestanding NIH institute with a mission statement that specifically addresses vision research. ARVO supports increased FY2011 NIH funding.

More Information

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Association of
American Cancer Institutes

**Written Testimony to the United States House of Representatives
Committee on Appropriations, Subcommittee on
Labor, Health and Human Services, Education and Related Agencies
Regarding FY 2011 Cancer-Related Funding
Submitted April 16, 2010**

Testimony submitted by:
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The Association of American Cancer Institutes (AACI), representing 95 of the nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the United States House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

AACI applauds recent budgetary commitments--notably, increased funding for NIH and support from the Obama Administration through the American Recovery and Reinvestment Act of 2009 (ARRA)--that have created a more encouraging landscape for cancer research compared to recent years. We hope that this support will continue in the years ahead, to ensure that this recognition of the importance of biomedical research is sustained.

AACI congratulates the administration and Congress on their commitment to ensuring quality care for cancer patients, as well as for providing researchers with the tools that they need to develop better cancer treatments and, ultimately, to cure this disease.

President Obama has released his FY2011 budget which includes a \$1 billion increase to the National Institutes of Health (NIH) budget for an expansion of support for biomedical research. This funding boost would make the NIH budget \$32.1 billion, representing a 3.2% increase. The National Cancer Institute (NCI) would receive an additional \$161 million, or 3.16% more, for a total of \$5.26 billion.

AACI has joined its colleagues in the biomedical research community in supporting the proposed increase for NIH and in calling on Congress to further strengthen the impact of the President's request by increasing funding to \$35 billion.

With the extra NIH and NCI funding, the cancer community will be better equipped to leverage ARRA financial support. ARRA dollars have helped to sustain the momentum achieved in reducing death rates from cancer, and they are proving to be an effective means of stimulating local economies and creating or maintaining jobs throughout the country.

For example, The Ohio State University Comprehensive Cancer Center and the Winthrop P. Rockefeller Cancer Institute at the University of Arkansas for Medical Sciences are moving forward with major construction projects supported by ARRA funding. Another AACI member, the University of New Mexico Cancer Center, is buying equipment and hiring more staff with ARRA money, while a researcher at Tennessee's Vanderbilt-Ingram Cancer Center is studying imaging techniques in colorectal cancer with help from ARRA grants (Association of American Cancer Institutes, *AACI Update*, February 2010).

Maintaining the flow of sufficient, dependable funding streams for NCI will help to continue the work that started under the stimulus plan. It will also serve as recognition that \$70 million worth of great ideas--the approximate amount of ARRA funding for NCI to date--might not have been explored if it were not for the administration's unprecedented infusion of funds for cancer research. And much untapped scientific potential remains.

Cancer Research: Benefiting all Americans

Cancer's financial and personal impact on America is substantial and growing-- one in two men and one in three women will face cancer in their lifetimes, and cancer cost our nation more than \$228 billion in 2008 (Centers for Disease Control and Prevention, *Addressing The Cancer Burden: At A Glance 2010*). This year, cancer will become the world's number one killer. Investing in cancer research is a prudent step - both for the health of our nation and for our nation's economic well-being.

Cancer research, conducted in academic laboratories across the country, saves money by reducing healthcare costs associated with the disease, enhances the United States' global competitiveness, and has a positive economic impact on localities that house a major research center. While these aspects of cancer research are important, what cannot be overstated is the impact cancer research has had on individuals' lives—lives that have been lengthened and even saved by virtue of discoveries made in cancer research laboratories at cancer centers across the United States.

Biomedical research has provided Americans with better cancer treatments, as well as enhanced cancer screening and prevention efforts. Some of the most exciting breakthroughs in current cancer research are those in the field of personalized medicine. In personalized medicine for cancer, not only is the disease itself considered when determining treatments, but so is the individual's unique genetic code. This combination allows physicians to better identify those at risk for cancer, detect the disease, and treat the cancer in a targeted fashion that minimizes side effects and refines treatment in a way to provide the maximum benefit to the patient.

In the laboratory setting, multi-disciplinary teams of scientists are working together to understand the significance of the human genome in cancer. For instance, the Cancer Genetic Markers of Susceptibility initiative is comparing the DNA of men and women with breast or prostate cancer with that of men and women without the diseases to better understand the diseases. The Cancer Genome Atlas is in development as a comprehensive catalog of genetic changes that occur in cancer.

These projects—along with the work being performed by dedicated physicians and researchers at cancer centers across the United States every day—have the potential to radically change the way cancer, as a collection of diseases, affects the people who live with it every day. Every discovery contributes to a future without cancer as we know it today.

Clinical Trials

Clinical trials are the cornerstone of cancer research, and it is commonly held that “yesterday’s clinical trials are today’s standard therapies”. Without clinical trials we cannot discover new cancer drugs and better treatments, and without volunteers we cannot conduct trials.

With no more than five percent of adult cancer patients participating in clinical trials, attracting volunteers to trials has been a long-standing struggle for cancer researchers. And yet, thanks in large part to advances realized through clinical trials, two-thirds of cancer patients now survive at least five years after diagnosis, compared with only half a generation ago.

Unfortunately, running a clinical trial from start to finish can be prohibitively complicated and expensive. While the nation’s cancer centers represented by AACI work to untangle red tape and other factors that can derail trials, a serious obstacle stands largely beyond their control—the cost to patients of participating in trials.

Section 2709 of the Patient Protection and Affordable Care Act of 2010 requires health insurance plans, including those offered through the Federal Employee Health Benefit Program, to provide coverage for routine costs associated with participation in clinical trials.

Commercial health insurers often refuse to pay for routine care costs associated with a clinical trial, arguing that the trial is “investigational” and thus optional or unnecessary. Consequently, patients experience financial difficulties that limit their participation in trials. That, in turn, has a negative impact on research and patients’ ability to receive promising treatments that are available through trials. It slows the development of new cancer therapies.

Routine costs associated with clinical trials include physician visits, blood work, hospital stays and x-rays. These costs would usually be reimbursed by the insurer if the patient was not participating in a clinical trial. The investigational portion of the trial (usually a new drug or device) is not charged to the patient or the insurer.

Since 1994, 27 states and the District of Columbia have passed laws requiring insurance coverage for routine patient care costs when patients participate in clinical trials, and another five

states have established cooperative agreements with insurers to do so. However, beyond the patchwork nature of such coverage, some of these laws do not necessarily require insurers to cover all cancer patients, such as those in Phase I or II clinical trials, or those with employer self-insured plans, in which a large company self-insures its employees. With the new federal policy, all cancer patients can now afford to enroll in a potentially life-saving clinical trial.

The Nation's Cancer Centers

The nexus of cancer research in the United States is the nation's network of cancer centers represented by AACI. These cancer centers conduct the highest-quality cancer research anywhere in the world and provide exceptional patient care. The nation's research institutions, which house AACI's member cancer centers, receive an estimated \$3.15 billion from NCI to conduct cancer research; this represents 65 percent of NCI's total budget (U.S. Department of Health and Human Services, National Institutes of Health, *National Cancer Institute 2008 Fact Book*). In fact, 84 percent of NCI's budget supports research at nearly 650 universities, hospitals, cancer centers, and other institutions in all 50 states. Because these centers are networked nationally, opportunities for collaborations are many—assuring wise and non-duplicative investment of scarce federal dollars.

Collaboration between the cancer centers' and NCI is also essential, and extramural input in shaping NCI's programmatic priorities is vital for effecting cancer research breakthroughs. Furthermore, AACI endorses the call for greater collaboration expressed in recent testimony by Robert S. DiPaola, MD, director of the Cancer Institute of New Jersey, delivered before the Health Subcommittee of the House Energy and Commerce Committee. The association is in strong agreement with Dr. DiPaola that "culture of collaboration" needs to be nurtured among NCI-designated cancer centers, as well as between such centers and the pharmaceutical and biotechnology companies that develop drug treatment for cancer and related illnesses.

In addition to conducting basic, clinical, and population research, the cancer centers are largely responsible for training the cancer workforce that will practice in the United States in the years to come. Much of this training depends on federal dollars, via training grants and other funding from NCI. Sustained federal support will significantly enhance the centers' ability to continue to train the next generation of cancer specialists—both researchers and providers of cancer care.

By providing access to a wide array of expertise and programs specializing in prevention, diagnosis, and treatment of cancer, cancer centers play an important role in reducing the burden of cancer in their communities. The majority of the clinical trials of new interventions for cancer are carried out at the nation's network of cancer centers.

Ensuring the Future of Cancer Care and Research

Because of an aging population, an increasing number of cancer survivors require ongoing monitoring and care from oncologists, and new therapies that tend to be complex and often extend life.

Demand for oncology services is projected to increase 48 percent by 2020. However, the supply of oncologists expected to increase by only 20 percent and 54 percent of currently practicing oncologists will be of retirement age within that timeframe. Also, alarmingly, there has been essentially no growth over the past decade in the number of medical residents electing to train on a path toward oncology as a specialty (American Society of Clinical Oncology, *Forecasting the Supply of and Demand for Oncologists: A Report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies, 2007*).

Without immediate action, these predicted shortages will prove disastrous for the state of cancer care in the United States. The discrepancy between supply and demand for oncologists will amount to a shortage of 9.4 to 15.1 million visits, or a shortage of 2,550 to 4,080 oncologists. (American Cancer Society, *Cancer Facts and Figures 2008*).

Cancer physicians—while essential—are only one part of the oncology workforce that is in danger of being stretched to the breaking point. For example, the Health Resources and Services Administration has predicted that by 2020, over 1 million nursing positions will go unfilled. The Department of Health and Human Services projects that today's 10-percent vacancy rate in registered nursing positions will grow to 36 percent, representing more than 1 million unfilled jobs by 2020.

Greater federal support for training oncology physicians, nurses, and other professionals who treat cancer must be enacted to prevent a disaster where demand for oncology services far outstrips the system's ability to provide adequate care for all.

Conclusion

These are exciting times in science and, particularly, in cancer research. The AACI cancer center network is unrivaled in its pursuit of excellence, and places the highest priority on affording all Americans access to superior cancer care, including novel treatments and clinical trials. It is through the power of collaborative innovation that we will accelerate progress toward a future without cancer, and research funding through the NIH and NCI is essential to achieving our goals.

**Statement by the Association of American Medical Colleges on
FY 2011 Appropriations for the Department of Health and Human Services
submitted to the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
April 14, 2010**

The Association of American Medical Colleges (AAMC) is a not-for-profit association representing all 131 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems; and nearly 90 academic and scientific societies. Through these institutions and organizations, the AAMC represents 128,000 faculty members, 75,000 medical students, and 110,000 resident physicians. The association appreciates the opportunity to address four programs that play critical roles in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: the National Institutes of Health (NIH); the Agency for Healthcare Research and Quality (AHRQ); health professions education funding through the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions; and the National Health Service Corps. The AAMC thanks the Subcommittee for its steadfast support of these programs.

National Institutes of Health -- The AAMC believes that the NIH is one of the nation's greatest achievements. The Federal government's unwavering support for medical research through the NIH has created a scientific enterprise that is the envy of the world and has contributed greatly to improving the health and well-being of all Americans -- indeed of all humankind.

The AAMC supports the Obama Administration's proposal to increase funding for NIH to \$32 billion in FY 2011. Boosting NIH's funding to a level that keeps pace with biomedical inflation recognizes the need for continued, predictable growth in this nation's medical research effort. At a time when our nation faces extraordinary fiscal challenges, the president's commitment to medical research is a wise investment that will yield long-term benefits for our nation's health. The partnership between NIH and America's medical schools and teaching hospitals continues to serve as the engine for this nation's search for an ever-greater understanding of the mechanisms underlying human health and disease. The foundation of scientific knowledge that continues to be built through NIH-funded research drives medical innovation that improves health and quality of life through new and better diagnostics, improved prevention strategies, and more effective treatments.

For example, a new ability to comprehend the genetic mechanisms responsible for disease is already providing insights into diagnostics and identifying a new array of drug targets. We are entering an era of personalized medicine, where prevention, diagnosis, and treatment of disease can be individualized, instead of using the standardized approach that all too often wastes health care resources and potentially subjects patients to unnecessary and ineffective medical treatments and diagnostic procedures.

Peer-reviewed, investigator-initiated basic research is the heart of NIH research. These inquiries into the fundamental cellular, molecular, and genetic events of life are essential if we are to make real progress toward understanding and conquering disease. Additional funding is needed to sustain and enhance basic research activities, including increasing support for current researchers and promoting opportunities for new investigators and in those areas of biomedical science that have historically been underfunded.

The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Clinical research not only is the pathway for applying basic research findings, but it often provides important insights and leads to further basic research opportunities. The AAMC supports additional funding for the continued expansion of clinical research and clinical research training opportunities, including rigorous, targeted post-doctoral training; developmental support for new and junior investigators; and career support for established clinical investigators, especially to enable them to mentor new investigators.

Anecdotal evidence suggests that changes in health care delivery systems and other financial factors pose a serious threat to the research infrastructure of America's medical schools and teaching hospitals, particularly for clinical research. The AAMC supports efforts to enhance the research infrastructure, including resources for clinical and translational research; instrumentation and emerging technologies; and animal and other research models.

The AAMC supports efforts to reinvigorate research training, including developing expanded medical research opportunities for minority and disadvantaged students. For example, the volume of data being generated by genomics research, as well as the increasing power and sophistication of computing assets on the researcher's lab bench, have created an urgent need, both in academic and industrial settings, for talented individuals well-trained in biology, computational technologies, bioinformatics, and mathematics to realize the promise offered by modern interdisciplinary research.

The AAMC is heartened by the Administration's proposals to provide a six percent stipend increase for predoctoral and postdoctoral research trainees supported by NIH's Ruth L. Kirschstein National Research Service Awards program. These stipend increases are necessary if medical research is to remain an attractive career option for the brightest U.S. students. Attracting the most talented students and postdoctoral fellows is essential if the United States is to retain its position of world leadership in biomedical and behavioral research.

As President Obama noted in his State of the Union address, "We need to encourage American innovation." Research conducted and supported by NIH has played a major role in the development of the biotechnology, pharmaceutical, and medical device industries and continues to provide the basis for their continued success. Sustaining this nation's investment in medical research will continue to strengthen our nation's economic health by creating skilled and high-paying jobs, new products and industries, and improved technologies. Further, as NIH Director Francis Collins, M.D., Ph.D., identified among his five themes for the agency, the research supported by NIH will benefit the nation's health care reform efforts and continue to improve the health and well-being of all Americans.

Agency for Healthcare Research and Quality – Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of health care, decrease health care costs, and provide access to essential health care services by translating research into measurable improvements in the health care system. The AAMC firmly believes in the value of health services research as the nation continues to strive to provide high-quality, efficient, and cost-effective health care to all of its citizens. The AAMC supports the president's request for AHRQ, which calls for \$611 million for the agency in FY 2011.

As the lead federal agency to improve health care quality, AHRQ's overall mission is to support research and disseminate information that improves the delivery of health care by identifying evidence-based medical practices and procedures. The funding increase proposed in the president's budget will allow AHRQ to continue to support patient-centered health research and other valuable research initiatives including strategies for translating the knowledge gained from patient-centered research into clinical practice, health care delivery, and provider and patient behaviors. These research findings will better guide and enhance consumer and clinical decision-making, provide improved health care services, and promote efficiency in the organization of public and private systems of health care delivery.

While we support a strong investment in patient-centered health research, we also encourage the Subcommittee to maintain balance across AHRQ's portfolio to allow the agency to support the full spectrum of activities aligned with its mission. For example, the president's budget does not continue funding for the Centers for Education and Research in Therapeutics (CERTs) grants, and instead, funds six new CERTs in the Patient-Centered Health Research portfolio and one new pediatric patient safety CERT. The AAMC believes AHRQ is perfectly positioned to take the lead on improving the quality of health care through the reduction of medical errors, and strongly supports the CERTs program; we encourage the Subcommittee not to limit or narrow its scope. The request also decreases other initiatives within the agency's "Crosscutting Activities" portfolio, including a proposed decrease for investigator-initiated research that would preclude AHRQ from offering any new grants in this area.

Additionally, in recent years, much of the funding for AHRQ has been derived from inter-agency transfers, rather than direct appropriations. The AAMC urges the Subcommittee to provide the majority of the agency's funding through direct appropriations.

Health Professions Funding – The AAMC thanks the Subcommittee for the increased support in recent years for the health professions and nursing education programs under Titles VII and VIII of the Public Health Service Act. These programs work to improve the diversity, distribution, and supply of the health professions workforce, with an emphasis on primary care and interdisciplinary training.

The AAMC is pleased that the Patient Protection and Affordable Care Act (P.L. 111-148) updated and restructured the existing Title VII and VIII programs to improve their efficiency, effectiveness, and accountability, and reauthorized them at funding levels that reflect the health workforce needs of the nation. To enable the programs to perform most optimally and help achieve the goals of the legislation, the AAMC joins the Health Professions and Nursing

Education Coalition (HPNEC) in support of an FY 2011 appropriation of at least \$600 million for the existing Title VII and Title VIII programs. This funding level will allow the programs to continue educating and training health professionals that are prepared to respond to the increased demand for health care services, improving access and quality of care across the country.

In addition to the existing health professions programs, the legislation authorizes several new programs and initiatives under Titles VII and VIII designed to mitigate health workforce challenges and expand the scope of the programs to additional fields. These new programs recognize the breadth of shortages across health care disciplines and aim to mitigate these existing and looming workforce shortages. The AAMC encourages the Subcommittee to support these new programs with an investment that supplements the support for the core of Title VII and VIII programs that have demonstrated their effectiveness.

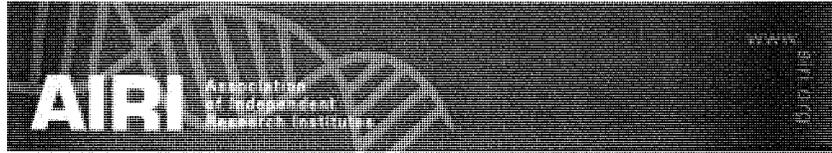
During their 40-year existence, the Title VII and VIII programs have created a network of initiatives across the country that supports the training of many disciplines of health providers. These are the only federal programs designed to create infrastructures at health professions schools and in their communities that facilitate customized training designed to bring the latest emerging national priorities to the populations at large and meet the health care needs of special, underserved populations. The AAMC urges the Subcommittee to continue its commitment to the Title VII and VIII health professions programs.

National Health Service Corps - The AAMC lauds the ambition of the Patient Protection and Affordable Care Act to provide up to \$414 million for the NHSC in FY 2011 through discretionary appropriations and the HHS Secretary's new Community Health Center (CHC) Fund.

The NHSC is widely recognized—both in Washington and in the underserved areas it helps—as a success on many fronts. It improves access to health care for the growing numbers of underserved Americans, provides incentives for practitioners to enter primary care, reduces the financial burden that the cost of health professions education places on new practitioners, and helps ensure access to health professions education for students from all backgrounds. Over its 39-year history, the NHSC has offered recruitment incentives, in the form of scholarship and loan repayment support, to more than 29,000 health professionals committed to serving the underserved.

In spite of the NHSC's success, demand for health professionals across the country remains high. At a field strength of 4,760 in FY 2009, the NHSC fell over 24,000 practitioners short of fulfilling the need for primary care, dental, and mental health practitioners in Health Professions Shortage Areas (HPSAs), as estimated by HRSA. While the "American Recovery and Reinvestment Act of 2009" (P.L. 111-5) provided a temporary boost in annual awards, this increase must be sustained to help address the health professionals workforce shortage and growing maldistribution.

The AAMC supports the President's FY 2011 budget request (\$169 million), which will ensure that the NHSC has access to additional dedicated funding through the HHS Secretary's CHC Fund. The AAMC further recommends that the Subcommittee include report language directing the Secretary to provide enhanced funding for the NHSC over the FY 2008 level, as directed under health care reform.



**Written Statement for the Record prepared for the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives**

**Fiscal Year 2011 Funding for the
National Institutes of Health, Department of Health and Human Service**

Submitted by:

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Sustained Support for NIH Research, Infrastructure, and Workforce

The Association of Independent Research Institutes (AIRI) respectfully submits this written testimony for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. AIRI appreciates the commitment that the Members of this Subcommittee have made to biomedical research through your strong support for the National Institutes of Health (NIH), and **recommends that you maintain this support for NIH in FY 2011 by providing the agency with a total discretionary budget of at least \$32.239 billion as requested by President Obama.** This would be a 3.2 percent increase over the FY 2010 enacted level.

AIRI is a national organization of 91 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and receive about 10 percent of NIH's peer reviewed, competitively awarded extramural grants. On average, AIRI member institutes receive a total of \$1.6 billion in extramural grants from NIH in any given year.

Through passage of the American Recovery and Reinvestment Act (ARRA) and recent year appropriations bills, Congress has taken important steps to jump start the Nation's economy through investments in science. Simultaneously, Congress is advancing and accelerating the

biomedical research agenda in this country by focusing on scientific opportunities to address public health challenges. NIH now has the ability to fund a record number of research grants, with special emphasis on groundbreaking projects in areas that show the greatest potential for improving health, including genetic medicine, clinical research, and health disparities. In addition, NIH is also funding construction projects and providing support for equipment and instrumentation, which is critically needed to update aging research facilities. We urge NIH to continue its commitment to facility, equipment, and infrastructure support. The infrastructure that we are creating needs to be maintained. Large fluctuations in funding will be disruptive to training, to careers, to long range projects and ultimately to progress. The research engine needs a predictable, sustained investment in science to maximize our return.

NIH is responding to its charge of stimulating the economy through job creation by supporting new scientists. The Recovery Act investments allowed us to see firsthand how research is impacting the economy. We cannot stop the momentum created by these historic investments. We need to be able to continue to advance the new directions charted with the ARRA support in 2011 and beyond.

Keeping up with the rising cost of medical research in the FY 2011 appropriations will help NIH begin to prepare for the "post-stimulus" era. In 2011 and beyond we need to make sure that the total funding available to NIH does not decline and that we can resume a steady, sustainable growth that will enable us to complete the President's vision of doubling our investment in basic research, which is why we are respectfully urging this Subcommittee to increase funding for NIH in FY 2011 by at least 3.2 percent.

AIRI's Commitment

Pursuing New Knowledge – The US model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory and translating them into medical advances that save lives. AIRI member institutes are private, stand-alone research centers that set their sights on the vast frontiers of medical science, specifically focused on pursuing knowledge about the biology and behavior of living systems and to apply that knowledge to extend healthy life and reduce the burdens of illness and disability.

High Throughput Technologies. AIRI Institutes have embraced technologies and research centers to collaborate on biological research for all diseases. Using advanced technology platforms or "cores," AIRI institutes use genomics, imaging, and other broad-based technologies for drug discovery.

Translational Research. Translational sciences bridges the divide between basic biomedical research and implementation in a clinical setting. Currently, over 15 AIRI member institutes are affiliated with and collaborate with the Clinical and Translational Science Awards (CTSA) Program. Many AIRI institutes also support research on human embryonic stem cells (hESC) with the hope of discovering new and innovative disease interventions.

Using Science to Enable Health Care Reform. As basic biomedical research institutes, AIRI members collaborate with other research partners on patient-centered outcomes research. AIRI members act as the basic research arm for disease treatment (for example, by supporting genetic testing), while other project collaborators study other aspects of disease intervention in an effort to learn the best practices for preventing and treating disease.

Global Health. AIRI member institutes focus on a wide range of diseases, many of which have a global affect on human health. Besides supporting research for the treatments, vaccines, and cures of the world's deadliest diseases, a number of AIRI institutes partner with research institutions in the developing world to support international disease research, such as collaborations on HIV/AIDS, Tuberculosis, and Malaria.

Reinvigorating the Biomedical Research Community. AIRI supports policies that promote the United States' ability to maintain a competitive edge in biomedical science. The biomedical research community is dependent upon a knowledgeable, skilled, and diverse workforce to address current and future critical health research questions. The cultivation and preservation of this workforce is dependent upon the ability to recruit scientists and students globally as well as training programs in basic and clinical biomedical research. Initiatives focusing on career development and recruiting a diverse scientific workforce are important to innovation in biomedical research for the benefit of public health.

Providing Efficiency and Flexibility – AIRI member institutes' small size and valuable flexibility provide an environment that is particularly conducive to creativity and innovation. In addition, independent research institutes possess a unique versatility/culture that encourages them to share expertise, information, and equipment across their institutes and elsewhere, which helps to minimize bureaucracy and increase efficiency when compared to larger degree granting academic universities.

Supporting Young Researchers – While the primary function of AIRI institutes is research, most are strongly involved in training the next generation of biomedical researchers and ensuring that a pipeline of promising researchers are prepared to make significant and potentially transformative discoveries in a variety of areas.

AIRI would like to thank the Subcommittee for its important work to ensure the health of the nation, and we appreciate this opportunity to present funding recommendations concerning NIH in the FY 2011 Appropriations bill. AIRI looks forward to working with Congress to carry out the research that will lead to improving the health and quality of life for all Americans.

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Written Testimony of
Association of Maternal and Child Health Programs (AMCHP)
to the

House of Representatives Committee on Appropriations, Subcommittee on Labor, Health
and Human Services and Education

Health Resources and Services Administration (HRSA), Maternal & Child Health Bureau
(MCHB)

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Chairman Obey and Distinguished Subcommittee Members:

I am grateful for this opportunity to submit written testimony on behalf of the Association of Maternal & Child Health Programs (AMCHP), our members, and the millions of women and children that are served by the Title V Maternal and Child Health Services Block Grant. My name is Dr. Phyllis Sloyer and I am the current President of AMCHP, as well a Division Director at the Florida Department of Health. I am asking the Subcommittee to support an increase in funding for the Title V Maternal and Child Health Services Block Grant to \$730 million for Federal Fiscal Year 2011.

To help illustrate the importance of Title V MCH Block Grant funding, I want to begin by sharing the story of a girl from Iowa who was helped by Title V-supported services:

Cora is a girl who was born 34 weeks prematurely. She was first seen at a Child Health Specialty Clinic when she was only 3 weeks of age. While at the clinic, she was diagnosed with plagiocephaly - sometimes referred to a "flat head syndrome." This problem occurs when a portion of an infant's skull becomes flattened due to pressure from outside forces and is not uncommon in premature infants. Workers at the clinic provided the new family with vital information on the disorder and what to expect. Cora was able to be seen by a pediatrician via telemedicine and was able to obtain a referral to see specialists in the treatment of plagiocephal. Cora is now 20 months old and likes to go to the local park and ride the merry-go-round. This same clinic that helped Cora and her family is supported by the Title V MCH Block Grant and would not be able to remain open without the funds and support that Title V funds offer. It is a great thing that families can come to a clinic close to their home, or be seen using health technology and be provided a complete physical, neurological, developmental evaluation for their kids.

This is just one example of the literally thousands of children, children with special health care needs and pregnant women that are served by Title V MCH Block Grant programs in the state alone. The Title V MCH Block Grant supports a similar network in my home state of Florida, and none of this could happen without Title V MCH Block Grant funding.

Health reform was a great step forward in advancing the health of women and children but America still faces huge challenges in improving maternal and child health outcomes and addressing the needs of very vulnerable children.

Reductions in maternal and infant mortality have stalled in recent years and rates of preterm and low birth weight births have increased over the last decade. Today the United States ranks 30th in infant mortality rates and 41st in maternal mortality when compared to other nations. Every 18 minutes a baby in America dies before his or her first birthday. Each day in America we lose 12 babies due to a Sudden Unexpected Infant Death. There are places in this country where the African-American infant mortality rate is double, and in some places even triple, the rate for whites. Preventable injuries remain the leading cause of death for all children, the U. S. still fails to adequately screen all young children for developmental concerns and childhood obesity has reached epidemic proportions, threatening to reverse a century of progress in extending life expectancy.

Health reform will increase coverage and work to improve access to health care and services for millions of Americans and Title V MCH Block Grant programs have the expertise to assure that women's and children's specific needs are addressed as programs are implemented. MCH is uniquely positioned to support and strengthen health reform by:

- *Ensuring that improvements in health, not just health care, are realized through health reform.* Coverage and access to medical care have only a limited impact on overall population health. Within the maternal and child health community, many states are seeing that early access to quality prenatal care services is no longer adequate to assure healthy birth outcomes for high-risk women. Despite expanded access to health care for pregnant women, the infant mortality rate in America has not improved significantly in the past decade. Programs funded by the Title V MCH Block Grant can help assure statewide implementation of primary prevention strategies including public information and education efforts targeted to populations at risk. Title V MCH Block Grant can help guide implementation of systems of comprehensive secondary prevention services (including newborn screening and counseling; regionalized systems of perinatal and neonatal high-risk services; high-risk tracking and follow-up services; early intervention services; and infectious disease control).
- *Offering leadership and support for outreach, enrollment, and access to family-centered care.* All children will now have health insurance coverage and Title V MCH Block Grant programs can help reach out to those children and their families to help them access the health care system. Since the 1990's Title V MCH leaders have been instrumental in supporting the Bright Futures initiative

that sets a standard of care for kids and children with special health care needs. In health reform, co pays for these preventive care and screening guidelines were eliminated, showing that Congress recognizes the importance of this national health promotion and Maternal and child health programs at the state level will support and promote The Bright Futures guidelines by offering training to children's health professionals. Many already insured individuals report they do not have a usual source of care. Only 50% of Children with Special Health Care Needs report that they receive comprehensive care within the context of a medical home and less than 20% of youth with special needs are able to find an adult health care provider who can appropriately care for them. Those with special needs often need additional services and care coordination not typically covered by health insurance.

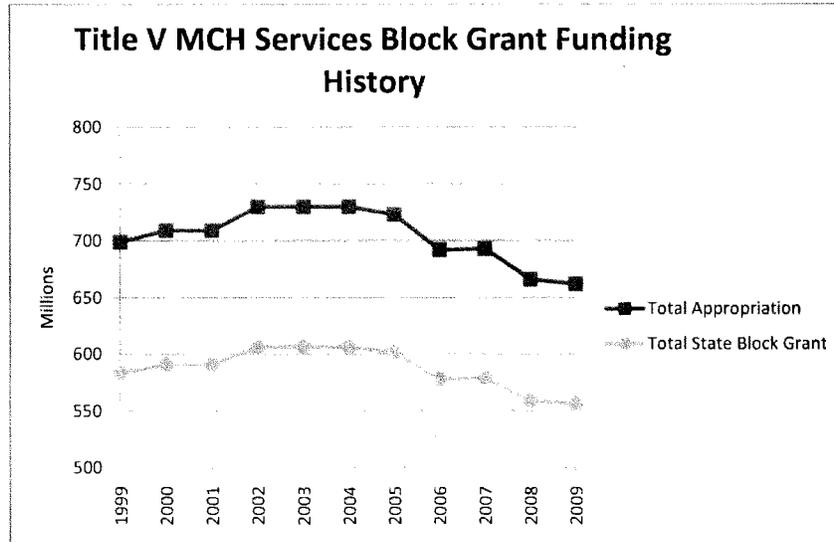
- *Assessing the health status of women and children* by conducting data collection, surveillance, and monitoring activities related to MCH population health measurement and outcomes. Title V MCH Block Grant programs regularly collect and report on public health measures, vital statistics, and personal health services data and use this information to inform state and local program planning.

Without increased funding, Title V MCH Block Grant Programs will be overwhelmed by this work if they are not provided the resources they need. AMCHP asks for your leadership in providing states the funding they need by increasing the Title V MCH Block Grant to \$730 million for FY 2011. We have a track record of demonstrating that we make a positive difference and are fully accountable for the funds that we receive. Increasing the funding to the Title V MCH Block Grant is an effective and efficient way to invest in our nation's women, children, and families.

The Office of Management and Budget found that Title V MCH Block Grant-funded programs deliver results and decrease the infant mortality rate, prevent disabling conditions, increase the number of children immunized, increase access to care for uninsured children, and improve the overall health of mothers and children. Close coordination with other health programs assures that funding is maximized and services are not duplicated.

Our results are available to the public through a national website known as the Title V Information System. Such a system is remarkably rare for a federal program and we are proud of the progress we have made.

However, despite the increasing demand for maternal and child health services, reductions to the Title V MCH Block Grant threaten the ability of programs to carry out their vital work. As states continue to face increasing economic hardship, more women and children will seek services through Title V MCH Block Grant funded programs. Due to years of reduced investment, the Title V MCH Block Grant is at its lowest funding level since 1993, \$662 million dollars, meaning states again are being asked to continue to serve additional people with less.



Crucial MCH activities are also supported by Title V under the Special Projects of Regional and National Significance (SPRANS) program, including MCH research, training, hemophilia diagnostic and treatment centers, and MCH improvement projects that develop and support a broad range of strategies. The SPRANS investment drives innovation for MCH programs and is an important part of the Title V MCH Block Grant.

Mr. Chairman and distinguished members, in closing I ask you to imagine with me an America in which every child in the United States has the opportunity to live until his or her first birthday; a nation where our Federal and state partnership has effectively moved the needle on our most pressing maternal and child health issues. Imagine a day when we are celebrating significant reductions or even the total elimination of health disparities by creatively solving our most urgent maternal and child health challenges. The Title V MCH Block Grant aims to do just that – using resources effectively to improve the health of all of America’s women and children. Investing in the Title V MCH Block Grant is a cost-effective investment in our nation’s future, and we again appreciate your leadership to fund it at \$730 million for Federal Fiscal Year 2011. Thank you.

Phyllis Sloyer RN, PhD, FAAP
President

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**Association of Organ Procurement Organizations
 Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
 Division of Transplantation, Health Systems Bureau, HRSA, Department of Health and
 Human Services**

The Association of Organ Procurement Organizations (AOPO) supports additional funding for the Division of Transplantation. AOPO is the non-profit, national organization that represents the nation's 58 federally-designated organ donation agencies through advocacy, support, and program development that will maximize the availability of organs and tissues. AOPO seeks to enhance the quality, effectiveness, and integrity of the donation process. The Division of Transplantation's mission is to provide oversight and guidance to the donation and transplantation regulations and processes in the United States, and, in that role, it enhances the efforts of AOPO and other organizations working to increase the number of lives saved through transplantation, research, education and therapy.

The timeliness of this funding request is particularly urgent. Organ donation saves lives. Since transplantation is standard therapy for end-stage organ failure, donation is a vital component of end-of-life care in the United States. There are almost 107,000 people waiting for a transplant in the U.S., eighteen of whom will die today while waiting for the gift of life. That equates to approximately one person dying every 90 minutes, an entirely preventable public health crisis.

In 2005, the Office of Management and Budget (OMB) set a federal goal to increase the number of organs donated annually by deceased individuals in the U.S. to 35,000 by 2012. In 2009, more than 24,000 organs were donated. As one of the catalysts in the donation process, organ procurement organizations (OPOs) must coordinate with all stakeholders to reach this federal goal. OPOs provide community education and programs to medical professionals to help them participate and support the donation process in every hospital in the United States. The hospital turns to the OPO for support and expertise when a donation situation presents itself. By law, OPOs must meet strict federal performance standards and operate within a regulated system under the Department of Health and Human Services.

Increasing organ availability in the U.S. can be achieved through several simultaneous strategies: enrolling all willing donors in donor registries; improving how donation from deceased donors is handled in U.S. hospitals; and by encouraging and protecting those who wish to donate organs while they are still alive.

Organ donation from deceased donors remains the most important source of increasing organ availability. Today, donation occurs in approximately 68% of eligible cases. This is up from 50% in 2003. OPOs now recover more than 3 organs per deceased individual. More increases can be achieved if the government and organ donation and transplantation professionals act on the changing nature of the organ donor pool. The increases in the incidence of obesity, diabetes and hypertension that affect the general public affect organ donors as well. It takes more resources to evaluate medically complex donation cases and it takes longer for recipients to recover from transplantation when these organs are received. Outdated federal regulations fail to

account for this new donation and transplantation reality, and do not go far enough to safeguard the potential supply of organs and tissues from possible unintended consequences. Performance outcome measures for transplant hospitals and OPOs must be risk-adjusted to account for the use of these donors with potentially compromising medical conditions. OPOs are already reimbursed on a cost-basis. Any reduction in payment would cause recovery costs to fall below the actual costs of procuring organs. Increased funding is critical to ensure that organ and tissue recovery does not decrease as a result of inadvertent consequences. New health care reform measures should not affect reimbursement policies by penalizing hospitals for potentially longer inpatient stays to manage transplant recipients with challenged donor organs because transplanting these organs is the optimal outcome for these patients.

Current OPO success measures are based on organs transplanted per donor and categorized by the type of donor. Preliminary work shows promise with a more objective and replicable evaluation system for OPOs. With additional funding, new tools can be developed that strengthen performance-based metrics and expand organ donation potential. To accomplish these goals, it is necessary for HHS officials and representatives of HRSA and CMS to partner with the donation and transplantation community to create a regulatory and reimbursement environment that fosters achievement of national performance goals.

The President's FY2011 Budget allocates \$4.0 million for Breakthrough Collaboratives on Organ Donation and Transplantation, initiatives that encourage teams of organ procurement, transplantation and critical care professionals to improve the organ donation and transplantation process in their local areas. OPOs must have the ability to identify, recruit, train, and financially support the involvement of critical care professionals (e.g. physicians, nurses, respiratory therapists) in local, regional, and national efforts to optimize donor organ function prior to donation. Best practices are shared for replication on a local level. More funding can and should be provided to ensure that health care professionals are properly trained to partner with OPO professionals to lead the donation process in their hospitals. We recommend that funding for the Collaboratives be increased from \$4.0 million to \$6.0 million to strengthen this national learning program.

The extra \$2 million appropriated to the Division of Transplantation in FY2010 was allocated to the OPTN (Organ Procurement and Transplantation Network) to develop strategies to increase living donation and establish a greater number of paired kidney programs. Although living donation is one way to increase the supply of scarce resources, and the \$2 million will make a positive impact, our country currently lacks the infrastructure to take full advantage of this donation option. Barriers to living donation remain. For example, there is no national living donor registry. Even more concerning, insurance companies can include living donation as a preexisting condition. Legislation to include prohibiting living organ donation as a preexisting condition for health insurance exclusions was introduced more than a year ago in both the House (H.R. 1558) and Senate (S. 623). Last June, a bill was introduced that would amend the Family and Medical Leave Act of 1993 to allow non-Federal employees up to 12 weeks of unpaid, job-protected leave in a 12-month period to provide living donation. Other methods to encourage living donation, such as the Living Organ Donor Tax Credit Act of 2009 (H.R. 218), have been proposed to allow incentives to encourage organ donation. Though this bill is stalled, it would

allow a non-refundable tax credit of up to \$5,000 for un-reimbursed costs and lost wages related to living donation. No action has been taken on any of these bills. Until this is done, it could be unwise to encourage more organ donation from living individuals.

OPOs and other agencies, such as Donate Life America, have tried to counterbalance the rising waiting list numbers by increasing the number of Americans who are registered organ and tissue donors. At the end of 2009, donor registrants in state registries topped 86.3 million. Donate Life America has just released a survey in early 2010 showing that 57% of U.S. adults support organ donation, a 7% increase from a 2009 survey. While 57% of Americans would sign up, only 37.1% have actually done so, indicating many do not know how to do so.

Representative Clay from Missouri proposed a bill (H.R. 3071) which authorized successful grants for the development, enhancement, expansion, and evaluation of State organ and tissue donor registries to aid in this effort to expand the donor pool. In addition, APOPO has worked with states to strengthen donor designation laws through efforts such as a nationwide effort to pass the revised Uniform Anatomical Gift Act (UAGA) in every state, and through a proposed resolution to the National Association of Attorneys General (NAAG). Donor registries have proven successful, but to close this gap, funding for public and professional education programs focused on increasing donor registrations should be extended from \$3.749 million to \$6.2 million.

Almost 107,000 people in the United States are waiting for lifesaving organ transplants, and every 11 minutes another name is added to the transplant waiting list. A million more suffer from conditions that could be successfully treated with donated corneas or tissue. The current system is not keeping pace with the critical shortage of vital organs in this country. Through additional funding for research, training and outreach, many more lives will be saved and improved.

The Division of Transplantation represents less than 0.35% of HRSA's discretionary budget authority, but adequate funding to help reach the HRSA national performance goals could amount to millions of dollars in savings to the Medicare program as a result of patients being freed from the requirement of long-term dialysis. These are the additional increases to the FY2011 Budget supported by APOPO:

- Additional funding for the Division of Transplantation should be granted. In order to reach federal goals, the pool of potential donors must be widened. OPOs are looking at numerous ways to increase organ donation. Some programs are taking advantage of extended criteria donors, while others are mastering other donation options such as donation after cardiac determination of death. In order to fully and safely explore these and other avenues to increase donation, funding for these and other programs must be specified. OPOs operate under strict governmental guidelines, which limit the amount of research and development OPOs can perform.
- Studies about the effect of potential health care reform measures should be conducted to guarantee organ recovery is not negatively impacted. We recommend that the \$500,000 to

conduct a study to define organ donor potential in the United States be increased to \$2 million.

- HRSA has not altered the types of organ donation grants in several years. We recommend that funding for new grant projects to increase organ donation be given \$10.2 million, up from \$7.2 million requested.

**Testimony of the Association of Public Television Stations (APTS) and
the Public Broadcasting Service (PBS)
Before the House Committee on Appropriations, Subcommittee on Labor, Health and
Human Services, Education and Related Agencies**

On behalf of America's 361 public television stations, we appreciate the opportunity to submit testimony for the record on the importance of federal funding for local public television stations.

Corporation for Public Broadcasting—FY 2013 Request: \$604 million, advance funded
More than 40 years after the inception of public television, local stations continue to serve as the treasured cultural institutions envisioned by their founders, reaching America's local communities with unsurpassed programming and services. Furthermore, the power of digital technology has enabled stations to greatly expand their delivery platforms to reach Americans where they are increasingly consuming media—online and on-demand—in addition to on-air.

However, at the same time that stations are expanding their services and the impact they have in their communities, stations are also facing unprecedented revenue declines—presenting them with the greatest financial challenge in their forty-year history. Every revenue source upon which our operations depend is under siege. State funding support is in a wholesale free-fall. Financial contributions from foundations and underwriters, at the local and national levels, have declined. Individual contributions, the bed-rock of every public station's annual operating budget, are dropping, reflecting the effects of rising unemployment and declining personal discretionary income. As such, increased federal support for public broadcasting is perhaps more important now than ever before.

Funds appropriated to CPB reach local stations in the form of Community Service Grants (CSGs). CSGs, while accounting for approximately 15 percent of the average station's overall budget, serve as the backbone of support for stations. Stations are also able to leverage those CSGs to raise additional funds from state legislatures, private foundations and their viewers.

Funding through CPB is absolutely essential to public television stations. A 2007 GAO report concluded that federal funding, such as CSGs, is an irreplaceable source of revenue, and that "substantial growth of nonfederal funding appears unlikely." It also found that "cuts in federal funding could lead to a reduction in staff, local programming or services."

Federal support for CPB and local public television stations has resulted in a nationwide system of locally owned and controlled, trusted, community-driven and community responsive media entities. For the seventh consecutive year, a 2010 Roper poll rated public television the most trusted institution among nationally known organizations. And in a recent report, the American Academy of Pediatrics recommended that Congress increase funding for public television, characterizing it as "the sole source for high quality, educational, noncommercial programming for children."

In addition, the advent of digital technology has created enormous potential for stations, allowing them to bring content to Americans in new, innovative ways while retaining our public service mission. Public television stations are now utilizing a wide array of digital tools to expand their

current roles as educators, local conveners and vital sources of trusted information at a time when their communities need them most.

For example, in an effort to address the decline of local journalism, CPB has just announced a significant investment in partnership with 28 local public television and radio stations to form seven regional journalism centers. The Centers will form teams of multimedia journalists, who will focus on issues of particular relevance to each region; their in-depth reports will be presented regionally and nationally via digital platforms, community engagement programs and radio and television broadcasts. For example, in the Plains, the project will focus on agribusiness including farming practices, food and fuel production. In the Upper-Midwest, the collaboration will focus on the changing economy of the region. In the Southwest, a bi-lingual reporting team will focus on cultural shifts that are transforming the southwest, including Latino, Native American and border issues.

In order for our stations to continue playing this vital role in their communities, APTS and PBS respectfully request \$604 million for CPB, advance funded for FY 2013. Advance funding is essential to the mission of public broadcasting. The longstanding practice ensures that stations are able to insulate programming decisions from political influence, leverage the promise of federal dollars to raise state, local and private funds, and have the critical lead-in time needed to plan and produce programs.

Digital Funding—FY 2010 Request: \$59.5 million

Public television stations have been at the forefront of the digital transition, embracing the technology early and recognizing its benefits to their viewers. Fortunately, Congress wisely recognized that the federally mandated transition to digital broadcast would place a hardship on public television's limited resources. Since 2001, Congress has provided public television stations with funds to ensure that they have the ability to continue to meet their public service mission and deliver the highest quality educational, cultural and public affairs programming post-transition.

Although the federally mandated portion of the transition is complete, what remains to be finished is the ability of stations to fully replicate in digital their analog services. As stations have completed the transition of their main transmitters, they will continue to convert their master controls, digital storage equipment and other necessary studio equipment—necessary to produce and distribute local educational programming. This program is also critical to providing funds that can be invested in interactive public media that maximizes investments in digital infrastructure—including such content investments as the American Archive.

Unlike most commercial broadcasters, public television has used this new public digital spectrum to maximize programming choices by offering an array of new channel options, including the national offerings of *V-me* (the first 24-hour, Spanish-language, educational channel), *World*, and *Create*.

More importantly, stations have also used these multicast capabilities to expand their local offerings with digital channels dedicated to community or state-focused programming. Some

stations have even utilized this technology to provide gavel-to-gavel coverage of their state legislatures. In addition, digital broadcasting has enabled stations to double the amount of noncommercial, children's educational programming offered to the American public.

APTS and PBS respectfully request \$59.5 million in CPB Digital funding for FY2011 to enable stations to fully leverage this groundbreaking technology.

Ready to Learn and Ready to Teach (U.S. Department of Education)

The President's budget proposed for the consolidation of both the Ready To Learn and Ready To Teach programs into larger grant programs. APTS and PBS are concerned that the consolidation of these programs could lead to, at worst, the elimination of these critical programs that Congress has seen fit to invest more than \$216 million since FY 2005. At best, under the proposed budget, these programs would cease to exist in their current structure, removing the mechanisms that have provided for the tremendous efficient and effective nature in which these programs successfully operate.

Consolidation or elimination of these programs would severely affect the ability of local stations to respond to their communities' educational needs, removing the needed resources provided by these programs for children, parents and teachers. For example, our stations that participate in Ready To Learn or Ready To Teach activities in places such as Iowa (Iowa Public Television), Wisconsin (Wisconsin ECB), Washington (KCTS 9), Louisiana (Louisiana Public Broadcasting), Illinois (WSIU, WEIU), Arkansas (AETN), Pennsylvania (WPSU, WQLN, WITF, WVIA), Mississippi (Mississippi Public Broadcasting), New Hampshire (New Hampshire Public Television), Texas (KLRN, KLRU, KAVC, KAMU, KEDT, KMBH, KUHT, KNCT, KTXT, KOCV, KWBU), Alabama (Alabama Public Television) and Tennessee (WLJT, WNPT) would be severely impacted by the proposed consolidation.

We urge that the Committee maintain the Ready To Learn and Ready To Teach programs as stable line-items in the FY 2011 budget and resist the calls for consolidation. Additionally, we encourage the Committee to express their support for Ready To Learn and Ready To Teach as stable, federally funded programs as Congress considers the reauthorization of the Elementary and Secondary Education Act which contains the authorizing language for both of these programs.

Ready To Learn—FY 2011 Request: \$32 million

With a specific target of at-risk children, Ready To Learn is improving the reading skills of all of America's children through fully researched, engaging educational television and on-line content, with a particular focus on over 150,000 low income households in 23 states and the District of Columbia. Ready To Learn content, based on the findings of the National Reading Panel of 2000, is on-air reaching 99 percent of the country's television households through Public Television stations as well as on-line, and on the ground in classrooms and communities.

In addition to successful on the ground partnerships with local stations, national nonprofit organizations and state education leaders, including the Council of Chief State School Officers, Ready To Learn's signature component is its research-based and teacher-tested television

programs that teach key reading skills, including: *SUPER WHY!*, *WordWorld*, *Martha Speaks*, *Sesame Street*, *Between The Lions*, and *The Electric Company* produced by the best educational children's content producers.

Recent evaluations of one such program, *SUPER WHY!*, tell a story of enormous success. The evaluation found that preschool children who watched the program performed significantly better on most of the standardized measures of early reading achievement when compared with those preschool children who watched an alternate program. In fact, pre-test to post-test gains averaged 28.7 percent for *SUPER WHY!* viewers compared with an average gain of 13.2 percent for alternate program viewers. Specifically, preschool children demonstrated significant growth in targeted early literacy skills featured in *SUPER WHY!*, including alphabet knowledge, phonological and phonemic awareness, symbolic and linguistic awareness, and comprehension.

In addition, *SUPER WHY!*'s 2008 five-day Summer Reading Camps -- 33 camps in 19 communities with 454 low-income Pre-K children -- produced measurable results in raising children's reading skills through their interaction with strategically executed instructional materials designed to boost letter knowledge, decoding, encoding and reading ability. During these camps, preschoolers showed an 84 percent gain in phonics skills and a 139 percent gain in word recognition skills.

A separate study conducted by the University of Michigan, found that low income children who were exposed to Ready to Learn content used in formal curriculum performed at nearly the same level as their higher income peers -- effectively erasing the achievement gap.

With additional funding, Ready To Learn can continue to meet the needs of those most lacking reading skills by extending the program's community engagement and partnership-driven work to additional high-need communities nationwide and by increasing capacity and reach through the innovative use of digital media.

APTS and PBS respectfully request \$32 million for Ready To Learn in FY2011.

Ready To Teach—FY 2011 Request: \$17 million

Ready To Teach was first introduced in Congress in 1994 as a demonstration project to show how distance learning technology coupled with public broadcasting's rich educational content could help teachers enhance their proficiency in specific curriculum areas.

Later authorized under the *No Child Left Behind Act*, Ready To Teach currently funds the development of digital educational services aimed at enhancing teacher performance. Through four Ready To Teach services—*PBS TeacherLine*, *e-Learning for Educators*, *VITAL* and *HELP*—PBS, Alabama Public Television, Thirteen/WNET and Rocky Mountain PBS (RMPBS), have provided online professional development targeted toward PreK-12 educators, video clips aligned to math and reading state standards, and an English-Language Learner program for math instruction.

Together, Ready To Teach programs have served nearly 500,000 educators since 2001, and represent an enormously successful utilization of innovative, digital technology for the benefit of teachers and their students in the 21st century classroom.

APTS and PBS respectfully request \$17 million in FY 2011 in order to build the library of professional development courses, resources and support materials for teachers through the public broadcasting infrastructure, and increase the number of local stations able to participate in Ready To Teach, thereby increasing the efforts to prepare highly qualified teachers.

Association of Rehabilitation Nurses
Written Testimony to the House Labor-Health and Human Services
Appropriations Subcommittee
Regarding Fiscal Year 2011 Nursing and Rehabilitation Related Funding
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April 16, 2010

Introduction

On behalf of the Association of Rehabilitation Nurses (ARN), I appreciate having the opportunity to submit written testimony to the House LHHs Appropriations Subcommittee regarding funding for nursing and rehabilitation related programs in fiscal year (FY) 2011. ARN represents 5700 Registered Nurses (RNs) with 10,000 nurses certified in the specialty who work to enhance the quality of life for those affected by physical disability and/or chronic illness. ARN understands that Congress has many concerns and limited resources, but believes that chronic illnesses and physical disabilities are heavy burdens on our society that must be addressed.

Rehabilitation Nurses and Rehabilitation Nursing

Rehabilitation nurses help individuals affected by chronic illness and/or physical disability adapt to their condition, achieve their greatest potential, and work toward productive, independent lives. They take a holistic approach to meeting patients' nursing and medical, vocational, educational, environmental, and spiritual needs. Rehabilitation nurses begin to work with individuals and their families soon after the onset of a disabling injury or chronic illness. They continue to provide support and care, including patient and family education, and empower these individuals when they return home, or to work, or school. The rehabilitation nurse often teaches patients and their caregivers how to access systems and resources.

Rehabilitation nursing is a philosophy of care, not a work setting or a phase of treatment. Rehabilitation nurses base their practice on rehabilitative and restorative principles by: (1) managing complex medical issues; (2) collaborating with other specialists; (3) providing ongoing patient/caregiver education; (4) setting goals for maximum independence; and (5) establishing plans of care to maintain optimal wellness. Rehabilitation nurses practice in all settings, including freestanding rehabilitation facilities, hospitals, long-term subacute care facilities/skilled nursing facilities, long-term acute care facilities, comprehensive outpatient rehabilitation facilities, and private practices, just to name a few.

To ensure that patients receive the best quality care possible, ARN supports federal programs and research institutions that address the national nursing shortage and conduct research focused on nursing and medical rehabilitation, e.g., traumatic brain injury. Therefore, ARN respectfully requests that the Subcommittee provide increased funding for the following programs:

Nursing Workforce and Development Programs at the Health Resources and Services Administration (HRSA)

ARN supports efforts to resolve the national nursing shortage, including appropriate funding to address the shortage of qualified nursing faculty. Rehabilitation nursing requires a high-level of education and technical expertise, and ARN is committed to assuring and protecting access to professional nursing care delivered by highly-educated, well-trained, and experienced Registered Nurses (RNs) for individuals affected by chronic illness and/or physical disability.

According to the Department of Health and Human Services, an estimated 36,750 nurses need to be recruited, educated, and retained through the federal Nursing Workforce Development program at the Health Resources and Services Administration (HRSA) to meet the current demands of the health care system. Efforts to recruit and educate individuals interested in nursing have been thwarted by the shortage of nursing faculty. In July 2008, the American Health Care Association reported that more than 19,400 RN vacancies exist in long-term care settings. These vacancies, coupled with an additional 116,000 open positions in hospitals reported by the American Hospital Association in July 2007, bring the total RN vacancies in the U.S. to more than 135,000. The demand for nurses will continue to grow as the baby-boomer population ages, nurses retire, and the need for healthcare intensifies. According to the U.S. Bureau of Labor Statistics, nursing is the nation's top profession in terms of projected job growth, with more than 587,000 new nursing positions being created through 2016. Furthermore, the Bureau of Labor Statistics analysts project that more than one million new and replacement nurses will be needed by 2016.

ARN strongly supports the national nursing community's request of \$267.3 million in FY 2011 funding for federal Nursing Workforce Development programs at HRSA.

National Institute on Disability and Rehabilitation Research (NIDRR)

The National Institute on Disability and Rehabilitation Research (NIDRR) provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. As one of the components of the Office of Special Education and Rehabilitative Services at the U.S. Department of Education, NIDRR operates along with the Rehabilitation Services Administration and the Office of Special Education Programs.

The mission of NIDRR is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDRR conducts comprehensive and coordinated programs of research

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and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities. NIDRR's focus includes research in areas such as: employment, health and function, technology for access and function, independent living and community integration, and other associated disability research areas.

ARN strongly supports the work of NIDRR and encourages Congress to provide the maximum possible FY 2011 funding level.

National Institute of Nursing Research (NINR)

ARN understands that research is essential for the advancement of nursing science, and believes new concepts must be developed and tested to sustain the continued growth and maturation of the rehabilitation nursing specialty. The National Institute of Nursing Research (NINR) works to create cost-effective and high-quality health care by testing new nursing science concepts and investigating how to best integrate them into daily practice. NINR has a broad mandate that includes seeking to prevent and delay disease and to ease the symptoms associated with both chronic and acute illnesses. NINR's recent areas of research focus include the following:

- End of life and palliative care in rural areas;
- Research in multi-cultural societies;
- Bio-behavioral methods to improve outcomes research; and
- Increasing health promotion through comprehensive studies.

ARN respectfully requests \$160 million in FY 2011 funding for NINR to continue its efforts to address issues related to chronic and acute illnesses.

Traumatic Brain Injury (TBI)

Approximately 1.5 million American children and adults are living with long-term, severe disability, as a result of traumatic brain injury (TBI). Moreover, this figure does not include the 150,000 cases of TBI suffered by soldiers returning from wars in Iraq and Afghanistan.

The annual national cost of providing treatment and services for these patients is estimated to be nearly \$60 million in direct care and lost workplace productivity. Continued fiscal support of the Traumatic Brain Injury Act will provide critical funding needed to further develop research and improve the lives of individuals who suffer from traumatic brain injury.

Continued funding of the TBI Act will promote sound public health policy in brain injury prevention, research, education, treatment, and community-based services, while informing the public of needed support for individuals living with TBI and their families.

ARN strongly supports the current work being done by the Centers for Disease Control and Prevention (CDC) and HRSA on TBI programs. These programs contribute to the overall body of knowledge in rehabilitation medicine.

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ARN urges Congress to support the following FY 2011 funding requests for programs within the TBI Act: \$10 million for CDC's TBI registries and surveillance, prevention and national public education and awareness efforts; \$8 million for the HRSA Federal TBI State Grant Program; and \$4 million for the HRSA Federal TBI Protection and Advocacy Systems Grant Program.

Conclusion

ARN appreciates the opportunity to share our priorities for FY 2011 funding levels for nursing and rehabilitation programs. ARN maintains a strong commitment to working with Members of Congress, other nursing and rehabilitation organizations, and other stakeholders to ensure that the rehabilitation nurses of today continue to practice tomorrow. By providing the FY 2011 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our nation has a sufficient nursing workforce to care for patients requiring rehabilitation from chronic illness and/or physical disability.



Written Testimony of Tamar Heller, Ph.D.,
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for the

House Appropriations
Labor, Health and Human Services, Education Subcommittee

April 23, 2010

This testimony summarizes the activities of and provides funding recommendations for the 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the Administration on Developmental Disabilities (ADD) within the Department of Health and Human Services and the 39 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB) within the Health Resources Services Administration.

Mr. Chairman, on behalf of the Association of University Centers on Disabilities (AUCD), I am pleased to submit this written testimony for the record both as a means to thank you for the Committee's support of our Centers over the past several years, and as a way of alerting you to the exciting developments happening now across the national network of University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs) and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs. These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They serve as a bridge between universities and their communities, bringing together the best of what current science has to offer to the challenges of children and adults living with disabilities in the community. By working together, programs engage in significant research that informs national policy and best practices. The network emphasizes national and international implementation of innovations in disability-related education, health care, and supports and services. It offers leadership on major social problems affecting all people with disabilities or special health needs.

I am Tamar Heller, Ph.D., Director of the University Center for Excellence in Developmental Disabilities at the Institute on Disability and Human Development at the University of Illinois at Chicago. I am submitting this testimony in my role as President of the AUCD Board of Directors.

First, let me describe the UCEDDs, one of the member networks of AUCD. The mission of the UCEDDs is to work with people with disabilities, their families, state and local government agencies, and community providers by engaging in training, technical assistance, service, research, and information sharing to build the capacity of communities to sustain all their citizens.

Since the 1960s, when Congress established a small number of research centers to study mental retardation, UCEDDs have grown into a national network of 67 Centers, each of which has developed its own area(s) of expertise based on the needs of the local community, their state, and the evolving expectations of people with disabilities to be full members of their communities. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402), UCEDDs currently serve as a national education, service, research, and information dissemination resource for our nation. The DD Act mandates that UCEDDs promote opportunities for individuals with developmental disabilities to exercise self-determination, and to be independent, productive, integrated citizens in all facets of community life. The UCEDDs meet these objectives by conducting research, providing training and technical assistance, and providing exemplary evidence-based direct services and supports. This includes state-of-the-art diagnosis and evaluation as well as support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, and employment.

Congress's investment in this valuable and effective network has been key to expanding inclusion of people with disabilities in American communities. AUCD urges the Congress to provide sufficient funds to continue to take advantage of this highly efficient and productive national network to address emerging critical national needs such as the alarming numbers of individuals diagnosed with Autism Spectrum Disorders. Nearly every UCEDD program provides

autism-related services; however the potential of the UCEDD network to provide additional autism-related supports has only begun to be tapped.

We also need to address our nation's racial and ethnic health and mental health disparities as well as inequities in access to services and supports. It is well documented that children and adults with developmental disabilities experience poorer health and more difficulty finding and paying for health care as compared to other populations. Our network has begun to partner with Minority Serving Institutions of Higher Education to better engage our research, education and service efforts for African Americans, Hispanic Americans, Native Americans, Pacific Islander and Asian Americans. Each of these populations has different levels of incidence and prevalence of diseases and disabilities that must be studied to produce optimal interventions and unique cultural issues including language, customs, and traditions that must be considered to designing services most likely to be effective. In partnership with existing UCEDDs, Minority Serving Institutions of Higher Education would be well positioned to train future leaders, conduct the necessary research, and disseminate pertinent and culturally relevant information targeted to diverse populations.

We are respectfully seeking an appropriation of \$44,000,000 under the ACF/ADD program for University Centers for Excellence in Developmental Disabilities (a \$5 million increase) which would allow up to four capacity-building grants of \$250,000 to enable up to four UCEDDs to work in partnership with collaborating Minority Serving Institutions (as defined in the Higher Education Act) to focus on research, health, education, and services for African Americans, Hispanic Americans, Native Americans, Pacific Islanders, Asian Americans, and other ethnically and culturally diverse populations. The increase would also help UCEDDs address critical, emerging national needs, such as the growing number of individuals with Autism Spectrum Disorders and related neurodevelopmental disorders; allow the Administration on Developmental Disabilities to compete two National Training Initiative grants on emerging national issues; and provide for a cost-of-living increase to the Centers.

Now I will address the Leadership Education in Neurodevelopmental and Related Disabilities--or LEND--programs. LEND programs are improving the health status of infants, children, and adolescents who have or at risk for neurodevelopmental and related disabilities, and their families. This is accomplished through the interdisciplinary training of professionals for leadership roles in the provision of health and related care, continuing education, technical assistance, research, and consultation. The LEND program focuses on the special health care needs of children with a wide range of neurodevelopmental, metabolic, and genetic disorders, including Autism Spectrum Disorder. Currently, there are 39 LENDs in 32 states and the District of Columbia. All LEND programs operate within a university system, many as part of a UCEDD or other larger entity, and are commonly affiliated with university hospitals, children's hospitals, or health care centers. This collaboration provides the programs with expert faculty, facilities, and other resources necessary to provide exceptional interdisciplinary training and services. Each LEND receives core funding from the Maternal and Child Health Bureau of the Health Resources and Services Administration of the U.S. Department of Health and Human Services. As a network, LENDs develop and promote best practices and produce exceptional clinicians and leaders in a variety of disciplines.

In 2006, Congress passed and the President signed the Combating Autism Act (CAA, PL 109-416) authorizing the Secretary to expand existing and develop new LENDs in states that did not have such a program. The intent of Congress was two-fold: to increase training on Autism Spectrum Disorder and other developmental disabilities for developmental pediatricians, clinical psychologists, other diagnosticians, and interventionists in states with LEND programs, and to establish new LEND programs with this charge in states that did not have a LEND program. HRSA began this expansion with the \$5.4 million appropriated in FY 2008 as part of its Autism and Other Developmental Disorders program by establishing four new LEND programs in Arkansas, Colorado, Connecticut, and Illinois and awarding 18 supplemental grants to existing LENDs to increase their Autism Spectrum Disorder-related training. The FY 2009 increase of \$2 million provided supplemental grants to 17 LENDs that had not received the previous year's supplement and to establish a new LEND in the state of Minnesota. The FY 2010 increase of \$2 million will continue the expansion of the network to establish up to two new LEND programs and to continue the award of supplemental grants for existing programs. The FY 2011 increase will continue the goals of the Combating Autism Act: to increase the number of professionals who are able to identify, assess, diagnose, and serve children with Autism Spectrum Disorders and other developmental disabilities. Much more needs to be done, but the CAA has helped LEND programs begin to better address the challenge of the increased numbers of children with autism.

Therefore, we are respectfully seeking an increase in funding that is specifically set aside for the LEND program to \$30,400,000 (a \$2 million increase) within the HRSA Autism and Other Developmental Disorders program. This additional funding will enhance the capacity of up to five existing LEND programs to expand their training of professionals in the interdisciplinary care and treatment of children with Autism Spectrum Disorder and related neurodevelopmental disabilities as well as provide funds to develop up to two new LEND programs in states that do not have one. This \$2 million would be part of the \$55 million authorized for HRSA activities in FY 2011 under the Combating Autism Act.

As I have stated, the UCEDD and LEND networks engage in education and training at the university and community level, conduct translational and applied research, and offer services to individuals and families. Please allow me this opportunity to provide you with some examples.

Training and Education - Nearly every aspect of individuals with disabilities' quality of life can be traced back to the work of well-trained professionals—teachers, clinicians, community service providers, etc. Positioned within universities, LEND and UCEDD programs provide interdisciplinary education to professionals-in-training and provide continuing education for professionals practicing in multiple fields. Whether the focus is on leadership, direct service, family-centered care, advocacy, cultural competence, clinical or administrative personnel training, these pre-service and continuing education programs are geared to the needs of students, practicing professionals, and families, and have been essential in raising and defining the educational standards of service across health, education, employment, and social service systems. In 2008, the network provided training to 3,560 students and fellows.

The Kansas Center for Autism Research and Training was initiated by the UCEDD in Kansas in 2008 to support research and training on the causes, nature and management of Autism

Spectrum Disorders. The Center has already launched an ambitious, new Autism Training Program geared to autism specialists, respite providers, family support providers and others working with individuals with Autism Spectrum Disorders and their families. The training program also is working with the state Department of Social and Rehabilitation Services to train skilled providers for the state's first Autism Waiver Program. With more trained providers, Kansas families struggling with the effects of Autism Spectrum Disorders will receive services where they need them, in their own homes and communities.

Research – UCEDDs engage in cutting edge research on a wide variety of issues related to individuals with developmental disabilities and their families. By studying areas such as brain development, Autism Spectrum Disorders, and early literacy, UCEDD researchers are studying how persons with disabilities learn and how best to teach them. UCEDDs lead in developing and evaluating promising practices that improve the lives of children and adults with disabilities and their families. Many are engaged in federal research projects on the causes and prevention of disabilities and chronic conditions and translate research into practice through the development and dissemination of informative products. In 2008, UCEDDs and LENDs operated 1,163 projects with a research component, including investigations into the efficacy of educational, behavioral, health, and technological interventions, policy analysis, and clinical trials.

In recent years, researchers working on neurodegenerative diseases such as Alzheimer's, Lou Gehrig's, Parkinson's have focused on astrocytes in their quest to help the brain protect itself from stressful conditions that are deadly to neurons. By shifting a normal protective mechanism into overdrive, a scientist at the UCEDD at the University of Wisconsin-Madison has completely shielded mice from a toxic chemical that otherwise would have caused Parkinson's disease. If scientists can determine how to fix a sick astrocyte, or even prevent a carrier from getting sick, they could offer profound protection against numerous neurodegenerative diseases.

Service – UCEDDs and LENDs provide direct services and supports to people with developmental and other disabilities, their families, and communities. This includes state-of-the-art diagnosis and evaluation and support services for children and adults in a wide range of areas including health, cognitive and behavioral development, education, daily living, and employment. In 2008, the network provided clinical services to 105,388 individuals and magnified this impact with an additional 146,438 consults on promising practices and supports to other providers.

The Delaware UCEDD's Early Learning Center is a nationally accredited, comprehensive early care and education clinical research facility serving 240 children, ages 6 weeks to 12 years, and their families, and specifically targeting children with risk factors, including poverty, foster care, and disabilities. In its fourth year, the Early Learning Center expanded to provide quality early care and education program for infants and toddlers in Wilmington's Southbridge area; provided a site for observation, practicum, and research to more than 5,000 undergraduate and graduate students from six UD colleges; and conducted more than a dozen interdisciplinary research projects on such topics as language acquisition, early literacy, parental discipline, maternal depression, and healthy eating and physical activity of preschoolers. The Early Learning Center's robot-assisted mobility study has been featured in a Discovery Channel

documentary and has attracted private partnership funding to help create mobility devices for children with disabilities under three years of age.

Another example of the services provided by the network is the State Employment Leadership Network, lead by the Institute for Community Inclusion, a Massachusetts UCEDD, with the state MR/DD agencies of 18 states. This multi-state initiative of the UCEDD provides technical assistance and promotes practices and policies to increase employment options for persons with disabilities.

Responding to National Needs – UCEDDs and LENDs are equipped to respond quickly to emerging national needs. They are currently expanding their work in the areas adult-acquired disabilities, particularly related to aging and military-combat, and they continue to work with the federal government on policies and initiatives to address the needs of people with disabilities in emergencies and disasters. Other national issues that have been addressed by UCEDDs and LENDs include positive behavioral interventions and supports, reading disorders in children, training programs for direct support personnel in developmental disabilities, and provision of training in methods to support employment for individuals with disabilities.

I again ask that you consider our request for funding of \$44 million for the network of UCEDDs and \$30,400,000 for the LENDs so that we may expand our network to more adequately serve our nation's growing population of Americans with developmental and other lifelong disabilities and to address our nation's health disparities.

Thank you for the opportunity to share this information about the UCEDDs and LENDs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

Sincerely,



Tamar Heller, PhD
President, AUCD

**Testimony Submitted on behalf of the
Association of University Programs in Occupational Health and Safety (AUPOHS)**

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President, Association of University Programs in Occupational Health and Safety

April 16, 2010

Thank you for the opportunity to submit testimony to the Subcommittee in support of funding for the National Institute for Occupational Safety and Health (NIOSH) and for the NIOSH-funded Education and Research Centers (ERCs). My name is Dr. Carol Rice. I am the director of the Cincinnati Education and Research Center located at the University of Cincinnati in Cincinnati Ohio and the President of the Association of University Programs in Occupational Health and Safety (AUPOHS).

I am testifying on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), an organization that represents 17 multi-disciplinary, university-based Education and Research Centers (ERCs) which are funded by NIOSH, the federal agency responsible for providing education and training for the prevention of work-related injuries and illnesses. The ERCs are regional resources for all parties involved with occupational health and safety – industry, labor, government, academia, and the general public. Collectively, the ERCs provide training and research resources to every Public Health Region in the United States. ERCs play the following roles in helping the nation reduce losses associated with work-related illnesses and injuries:

- **Prevention Research**: Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.
- **Professional Training**: Graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines.
- **Research Training**: Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.
- **Continuing Education**: Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines. These courses are delivered throughout the regions of the 17 ERCs as well as through distance learning technologies.
- **Regional Outreach**: Responding to specific requests from local employers and workers on issues related to occupational health and safety.

The Scope of the Problem of Occupational Injury and Illnesses

The many causes of occupational injury and illness represent a striking burden on America's

health and well-being. Yet, despite significant improvements in workplace safety and health over the last several decades:

- Each day, an average of 9,000 U.S. workers sustain disabling injuries on the job, 16 workers die from an injury suffered at work, and 137 workers die from work-related diseases. Only recently, 29 miners died in one day in West Virginia.
- In 2005, more than 4.2 million workers sustained work-related injuries and illnesses in the private sector alone.
- The Liberty Mutual 2005 Workplace Safety Index estimates that employers spent \$50.8 billion in 2003 on wage payments and medical care for workers hurt on the job; the indirect costs exceeded \$200 billion.

This is an especially tragic situation because **most work-related fatalities, injuries and illnesses are preventable** with effective, professionally directed, health and safety programs.

Here are some of the important issues that NIOSH deals with:

- When the Senate office buildings were attacked with anthrax, NIOSH and ERC professionals responded.
- NIOSH, helped by ERCs, took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia.
- We are now seeing serious health problems in the workers who were at Ground Zero. NIOSH and the New York - New Jersey ERC are playing the major lead in their medical follow-up. Health exams of affected workers have also been conducted at other ERCs.
- NIOSH is the leading federal agency conducting research and providing guidance on the worker health implications in the emerging field of nanotechnology.

We need manpower to address the sorts of issues mentioned above and it is the NIOSH ERCs that produce the graduates who fill key positions in health and safety programs, regionally and around the nation. And because ERCs provide training that is multi-disciplinary, ERC graduates protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training such qualified professionals, the country continues to have ongoing shortages.

Furthermore, we do not live in a static environment. The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72 percent to over 31 million. Work related injury and fatality rates begin increasing at age 45, with rates for workers 65 years and older nearly three times as high as the average for all workers. The rapid development of nanotechnology poses a number of unanswered questions with regard to workplace risk factors that the science or workplace safety

and health will have to answer.

In addition to factors that increasingly affect the vulnerability of our workers, we constantly face new threats to worker health. As an example, one of the greatest concerns regarding a potential outbreak of avian influenza is the drastic effect it may have on our workforce. The protection of health care workers in particular will become a major priority if we are to protect our population.

Despite being the primary federal agency for occupational disease and injury prevention in the nation, NIOSH receives only about one dollar per worker per year for its mission of research, professional education, and outreach.

Homeland Security

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing occupational safety and health professionals to identify and ameliorate vulnerabilities to terrorist attacks and other workplace hazards and increase readiness to respond to biological, chemical, or radiological attacks.

Thanks to the Subcommittee's support for occupational health and safety research, NIOSH developed more effective methods to test for anthrax contamination in congressional offices. These procedures were quickly adopted by the Coast Guard, the FBI, and government building contractors. More recently, in response to ongoing safety concerns regarding the tunnels under the U.S. Capitol Complex, NIOSH was asked to evaluate health hazards in the tunnels for workers who maintain the plumbing that provides steam and chilled water to Congress, the Library of Congress, the Supreme Court and other federal buildings.

In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize losses in the event of a disaster. NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and conducting ongoing activities to safeguard the health of clean-up workers. Additionally, NIOSH is now administering grants to provide health screening of World Trade Center responders. Included in the grantees is the New York - New Jersey ERC.

In the face of the growing concerns surrounding homeland security, ERCs have rapidly upgraded research coordination and expanded training opportunities, including sponsoring national and regional forums on response to bioterrorism and other disasters.

The Need for Occupational Safety and Health Manpower

The NIOSH ERCs were reviewed by the DHHS Office of the Inspector General in 1995. The resulting report affirmed the efficacy of the ERCs in producing graduates who pursue careers in occupational safety and health. Since the ERCs are regional, they are ready to respond to various trends in industries throughout the country. In the southeast, for example, automobile manufacturing has been the major growth industry since 2000. Alabama now has major facilities

for Mercedes, Honda and Hyundai that employ thousands of workers. Graduates from the Deep South Education and Research Center fill key positions in the safety, health and environmental programs at all of these facilities. And because they provide training that is multi-disciplinary, ERCs graduate professionals can protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training qualified occupational health and safety professionals, the country continues to have ongoing shortages. The manpower needs are especially acute for doctoral-level trained professionals who can conduct research and help in implementing the National Occupational Research Agenda (NORA).

In May 2000, the Institute of Medicine issued its final report on the education and training needs for occupational safety and health professionals in the United States. This report concluded that “the continuing burden of largely preventable occupational diseases and injuries and the lack of adequate occupational safety and health services in most small and many larger workplaces indicate a clear need for more occupational safety and health professionals at all levels.” Specific needs identified by the IOM report include:

- An insufficient number of doctoral-level graduates in occupational safety, thus limiting the nation’s capacity to perform essential research and training in traumatic injury prevention.
- An inability to attract physicians and nurses into formal occupational safety and health academic training programs, thus limiting the resources needed to deliver occupational health services.

ERCs are accomplishing the critical mission of filling these gaps by preparing expert researchers and practitioners in occupational safety and health.

Recommendation for Fiscal Year 2011

In fiscal year 2011 AUPOHS requests \$423.171 million, a \$50 million increase over the Fiscal Year 2010 total program level for the National Institute for Occupational Safety and Health (NIOSH). Within the recommended NIOSH total appropriation, we respectfully request that the Committee provide not less than \$34.37 million for Education and Research Centers (ERCs), which represents a \$10 million increase over the Fiscal 2010 level.

A \$50 million increase would enable NIOSH to keep pace with the changing nature of work and the workforce and ensure that research and education to prevent work-related disease and injuries remains a high priority. Given that much of NIOSH’s extramural research program is carried out by the Education and Research Centers (ERCs), sustaining the academic infrastructure provided by the ERCs is essential. Our recommendation would ensure that our nation’s universities have the capacity and manpower to implement these initiatives and expand training programs to improve the health and productivity of American workers.

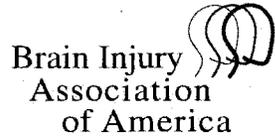
The ERCs play an essential role in prevention health research and the training of occupational safety and health professionals, many of which are in short supply. The 17 ERCs are distributed throughout the U.S. and have a critical community outreach function, as well as serve as local

resources of occupational safety and health expertise. A \$10 million increase will bring the total budget for the 17 ERCs to \$34.37 million and promote achievement of the NIOSH strategic goal to increase the technical proficiency of the occupational safety and health professionals who lead occupational safety and health practice in both the private and public sectors.

Thank you for the opportunity to report the great need for research and training in occupational safety and health.

NIOSH-supported Education and Research Centers (ERCs)

- Alabama Education and Research Center (*UA at Birmingham, Auburn University, University of Alabama*)
- Northern California Education and Research Center (*UC Berkeley, UC Davis, UCSF*)
- Southern California Education and Research Center (*UCLA and UC Irvine*)
- Cincinnati Education and Research Center (*University of Cincinnati*)
- Mountain and Plains Education and Research Center (*University of Colorado Denver (CU), Colorado State University (CSU), National Jewish Medical and Research Center (NJMRC), Denver Health and Hospital Authority (DHHA), Univ. of New Mexico Health Sciences Center*)
- Harvard Education and Research Center
- Illinois Education and Research Center (*University of Illinois at Chicago*)
- Heartland Center for Occupational Health and Safety (*University of Iowa*)
- Johns Hopkins Education and Research Center
- Michigan Education and Research Center (*University of Michigan*)
- Midwest Center for Occupational Health and Safety (*University of Minnesota*)
- New York /New Jersey Education and Research Center (*Mount Sinai School of Medicine, Hunter College School of Health Sciences, New Jersey Institute of Technology, New York University, University of Medicine and Dentistry of New Jersey*)
- North Carolina Occupational Safety and Health ERC (*UNC at Chapel Hill*)
- Sunshine ERC (*University of South Florida*)
- Southwest Center for Occupational and Environmental Health (*University of Texas*)
- Rocky Mountain Center for Occupational and Environmental Health (*University of Utah*)
- Northwest Center for Occupational Health and Safety (*University of Washington*)



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Creating a better future through brain injury prevention, research, education and advocacy

Sarah C. D'Orsie
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Brain Injury Association of America
703-584-8637
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April 7, 2010

The Honorable Dave Obey
Chairman
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable Todd Tiaht
Ranking Member
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies
1016 Longworth House Office Building
Washington, DC 20515

Dear Chairman Obey and Ranking Member Tiaht:

Thank you for the opportunity to submit this written testimony with regard to the FY 2011 Labor-HHS-Education appropriations bill. My testimony is on behalf of the Brain Injury Association of America (BIAA), our national network of state affiliates, and hundreds of local chapters and support groups from across the country.

A traumatic brain injury (TBI) is a blow or a jolt to the head that temporarily or permanently disrupts brain function – i.e. who we are and how we think, act, and feel. In the civilian population alone every year, more than 1.5 million people sustain brain injuries from falls, car crashes, assaults and contact sports. Males are more likely than females to sustain brain injuries. Children, teens and seniors are at greatest risk.

Recently, we are seeing an increasing number of service members returning from the conflicts in Iraq and Afghanistan with TBI, which has been termed one of the signature injuries of the War. A recent study conducted by the RAND Corporation found that 320,000 troops, or 19% of all service members, returning from Operations Enduring Freedom and Iraqi Freedom may have

experienced a traumatic brain injury during deployment. Many of these returning service members are undiagnosed or misdiagnosed and subsequently they and their families will look to community and local resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into the community.

For the past 13 years Congress has provided minimal funding through the HRSA Federal TBI Program to assist States in developing services and systems to help individuals with a range of service and family support needs following their loved one's brain injury. Similarly, the grants to state Protection and Advocacy Systems to assist individuals with traumatic brain injuries in accessing services through education, legal and advocacy remedies are woefully underfunded. Rehabilitation, community support and long-term care systems are still developing in many States, while stretched to capacity in others. Additional numbers of individuals with TBI as the result of war-related injuries only adds more stress to these inadequately funded systems.

BIAA respectfully urges you to provide States with the resources they need to address both the civilian and military populations who look to them for much needed support in order to live and work in their communities.

With broader regard to all of the programs authorized through the TBI Act, BIAA specifically requests:

- **\$10 million** (+ \$4 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness
- **\$8 million** (+ \$1 million) for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program
- **\$4 million** (+ \$1 million) for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program

CDC – National Injury Center - The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 1.4 million TBIs occur each year and 3.4 million Americans live with a life-long disability as a result of TBI. In addition, the TBI Act as amended in 2008 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds states for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in helping standardize evidence based guidelines for the management of TBI and \$3 million of this request would go to fund CDC's work in this area as well as support a pilot project to improve hospital compliance with existing guidelines.

HRSA TBI State Grant Program - The TBI Act authorizes the HHS, Health Resources and Service Administration (HRSA) to award grants to (1) states, American Indian Consortia and territories to improve access to service delivery and to (2) state Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past thirteen years the HRSA Federal TBI State Grant Program has supported state efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions

In FY 2009, HRSA reduced the number of state grant awards to 15, in order to increase each monetary award from \$118,000 to \$250,000. This means that many states that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increasing the program to \$8 million will provide funding necessary to sustain the grants for the 15 states currently receiving funding along with the three additional states added this year and to ensure funding for four additional states. Steady increases over five years for this program will provide for each state including the District of Columbia and the American Indian Consortium and territories to sustain and expand state service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), service coordination and other necessary services and supports identified by the state.

HRSA TBI P&A Program - Similarly, the HRSA TBI P&A Program currently provides funding to all state P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information & referral and legal assistance to people residing in nursing homes, to returning military seeking veterans benefits, and students who need educational services.

Effective Protection and Advocacy services for people with traumatic brain injury is needed to help reduce government expenditures and increase productivity, independence and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. A \$4 million appropriation would ensure that each P&A can move towards providing a significant PATBI program with appropriate staff time and expertise.

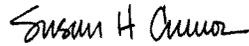
NIDRR TBI Model Systems of Care - Funding for the TBI Model Systems in the Department of Education is urgently needed to ensure that the nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a "proving ground" for future researchers.

In order to make this program more comprehensive, Congress should provide **\$11 million** (+ \$1.5 million) in FY 2011 for NIDRR's TBI Model Systems of Care program, in order to add one new Collaborative Research Project. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDRR budget.

We ask that you consider favorably these requests for the CDC, the HRSA Federal TBI Program, and the NIDRR TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist states in coordinating services, protect the rights of persons with TBI, and bolster vital research.

Sincerely,



Susan H. Connors, President/CEO
Brain Injury Association of America



Center for Civic Education

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**Testimony submitted by the Center for Civic Education, Charles N. Quigley,
Executive Director to the Subcommittee on Labor, Health and Human Services,
Education, and Related agencies regarding appropriations for the U.S. Department
of Education**

I appreciate the opportunity to present this testimony requesting continued support of \$35 million (the same amount as FY 2010) for the civic education program (Elementary and Secondary Education Act, Sections 2341-2346) that the U.S. Department of Education (ED) cut from its FY2011 budget request to Congress. I am Charles N. Quigley, executive director of the Center for Civic Education (Center), the principal organization supported under the Education for Democracy Act.

Other worthy organizations supported under the Act include the Center on Congress at Indiana University (COC), the National Conference of State Legislatures (NCSL), the Council for Economic Education, and a domestic network of public- and private-sector organizations in every state and congressional district in the nation. Together with the Center, these organizations provide effective programs in civic and economic education to millions of students annually at precollegiate levels in the United States and in more than 80 emerging and advanced democracies throughout the world.

The justification for the elimination of funding for the civic education program, namely, that such activities would be continued through a consolidated competitive program of relatively small grants, is not supported by the facts. Furthermore, it overlooks the valuable national infrastructure of programming—supported by Congress through many years of directed funding—that would be lost without this sustained investment. The national program funded under the Education for Democracy Act is implemented with the assistance of an extensive network of state and congressional district coordinators that provides equal support to schools in every congressional district in the form of free curricular materials, assistance in professional development, and other technical assistance. This equal support for schools in each congressional district would not be available under the proposed consolidation plan.

The Education for Democracy Act

The Education for Democracy Act (EDA) supports highly successful national and international projects authorized and approved by the U.S. Congress and funded by the U.S. Department of Education. Since 1987, directed funding from the EDA has ensured that more than 30 million students across the nation have been taught the principles of American constitutional democracy through the We the People: The Citizen and the Constitution program and related programs. In addition, millions of students in emerging

democracies throughout the world have benefitted from the civic and economic education exchange programs supported by the EDA. The proposed elimination of this directed funding in favor of competitive grants to numerous smaller initiatives would ensure the destruction of this proven, exemplary domestic civic education program representing twenty-two years of federally funded investment.

Congress has long recognized that directed funding is essential for certain large-scale projects of national significance. The improvement of civic education in the United States and the establishment of effective civic and economic education programs in emerging democracies require a large-scale, long-term program involving the establishment of extensive national implementation networks supported by highly skilled, experienced, and dedicated staff. It would be grossly inefficient and extremely difficult to achieve the goals of such programs through a number of relatively small and uncoordinated grants with two- to five-year timelines.

The civic education programs (We the People and related programs), authorized by the EDA, are

- cost effective;
- validated by independent research;
- effective in raising student academic achievement in schools throughout the country;
- implemented nationwide in every congressional district;
- administered locally by dedicated volunteers;
- supported by professional development for teachers;
- providers of free, high-quality curricular materials for students and teachers; and
- supported by Congress and numerous national, state, and local public- and private-sector groups.

Furthermore, the Cooperative Education Exchange Program's international civics programs

- promote U.S. foreign policy objectives in more than 80 countries,
- encourage respect for human rights, and
- promote commitment to democratic values and principles in emerging democracies.

Benefits of the Domestic Programs

Cost-effective civic education in every congressional district. Over twenty-two years, the EDA has ensured the civic education of more than 30 million students nationwide. On average, in each congressional district the existing program annually supports

- a total of 5,700 students;
- in 190 classes at the elementary, middle, and high school levels;
- at a cost of \$7.20 per student—far less than the retail cost of one history or civics textbook.

Note: The program currently reaches approximately 2.5 million students each year. It is highly unlikely that a competitive, relatively small grant program would reach as many students in every congressional district of the nation as cost effectively as the We the People Programs.

Proven impact on student outcomes. The We the People Programs are independently proven to be effective. Evaluations by the Educational Testing Service, Stanford University, RMC Research Corporation, and others have shown that the We the People Programs have had a statistically significant positive effect on student knowledge, skills, dispositions, and behaviors (see www.civiced.org/research).

Note: To place the funding for these programs in a competitive grant program would be to discard proven programs developed and implemented with federal dollars in favor of numerous smaller programs that lack any independent evidence of proven effectiveness.

National network. The We the People Programs have grassroots community support in every congressional district. They are implemented by a national civic education network of

- 120 public- and private-sector organizations in all fifty states and the District of Columbia and
- 623 representatives of local education agencies or civic-minded community groups at the congressional-district level.

Note: In every state, the We the People Programs are supported by an extensive network of civic educators and community volunteers who administer the programs and raise funds to support local program activities. This network would cease to exist if its funding were to be placed in a competitive grant program.

Effective use of federal dollars. Approximately 70 percent of the funding for the program is distributed equitably to every congressional district. The funds provide

- free curricular materials for elementary, middle, and high schools;
- professional-development programs for teachers; and
- funding at the state and congressional-district levels for the implementation of curricular programs in civic education.

Note: A competitive program of relatively small grants would not result in such an effective and equitable distribution of resources. Instead, many congressional districts would receive little or no assistance in implementing civic education programs.

In addition, funding relatively large nationwide programs—such as the We the People Programs—compared to funding numerous smaller programs is more likely to be cost effective in controlling administrative costs and providing more funding for programmatic costs. As noted above, approximately 70 percent of the funds the

Center received for its USED-supported programs were spent for programmatic costs throughout the United States. The remaining 30 percent consists of staff and benefits (approximately 20 percent) and general administrative costs (approximately 10 percent). Of the staff costs, some are for general administration, but a considerable amount is for technical assistance to state and local programs for such purposes as professional development and evaluation.

Curriculum backed by professional development of teachers. The Center sponsors professional development activities throughout the nation with the assistance of a national network of directors, mentor teachers, and scholars. These activities range in length from less than one day to seven days. Participants explore content, teaching methods, and assessment strategies. Free materials are provided for participants.

Innovative content and methods. The We the People program is the first curriculum based entirely on constitutional principles and history. Students take part in a competition on constitutional topics that takes the form of simulated congressional hearings. This is an educational innovation that works. There is no other civic education competition in the world comparable to the We the People program.

Note: Elimination of directed EDA funding for We the People would mean the elimination of district, state, and national simulated congressional hearings, during which students compete in a test of knowledge and understanding of contemporary and historical issues surrounding the Constitution. These hearings have inspired students to choose lives of active citizenship, public service, and civic engagement.

Adherence to authorizing language. Congress recognized the national need for programs that develop a reasoned commitment to American constitutional democracy and the ability of young people to participate competently and responsibly in the political life of the nation. The programs supported under the EDA have demonstrated their efficacy in promoting such goals.

Note: To eliminate support for these proven, effective programs and place their funding into a competitive grant program would be to withdraw the long-term investment of the federal government in programs proven to yield high returns. Federal funding would instead be spent on unproven programs with unpredictable outcomes.

Benefits of the International Programs

Promoting U.S. foreign policy objectives abroad. The Cooperative Education Exchange Program's civics and economics programs help to institutionalize democratic ideals in more than 80 emerging and established democracies worldwide. These highly successful programs, helping to meet the U.S. foreign policy objectives of promoting democracy, human rights, and an understanding of the principles of market economies and their relationship to democracy are not mentioned in the ED alternative, thereby ignoring the intent of Congress to support these critical programs.

International network for democracy promotion. The Civitas International Exchange Program created a network of international public- and private-sector organizations and colleagues and their American counterparts in thirty states. The members of this network work in unison to translate and adapt civics textbooks to help educational systems in emerging democracies teach democratic principles and values. Without the support of the EDA, the network would be eliminated and highly effective programs in these emerging democracies would be deprived of the support needed for their institutionalization. It is estimated that these programs reach 1.5 million students each year at a cost of \$3.00 per student.

Conclusion

The Education for Democracy Act programs have been highly scrutinized by Congress since their inception in 1987 and have undergone multiple authorizations in the law and annual approval in the appropriations process. They have survived multiple sessions of Congress and several administrations, including initiatives to downsize and reinvent government. Recent “Dear Colleague” letters in support of the EDA routinely received the support of more than 100 members of the House and nearly half of the Senate. There are compelling reasons for this support that ultimately reflect a simple truth—the programs have a proven track record of success in furthering support for democracy; fostering competent and responsible participation by students in the political life of their communities, states, and nations; raising student academic achievement; improving teacher quality; and providing schools with free, exemplary curricular programs and technical assistance.

Support for a Competitive Civic Education Grant Program

The Center supports the establishment in ED of a competitive grant program in civics and government in addition to continued support for the current programs. There are many other public- and private-sector agencies working in the field of civic education worthy of support. A large percentage of these groups are colleagues and participants in the Center’s domestic networks. A new, competitive grant program could result in the development and promulgation of new ideas and programs to enhance the field. Such support from both the public and private sectors, in fact, gave the Center its start in 1965. The Center is working with representatives of other organizations in the field to support the inclusion of a competitive grant program in the reauthorization of the Elementary and Secondary Education Act.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) COALITION
 C/o Don Hoppert, American Public Health Association 800 I Street, NW, Washington, D.C. 20001 (202) 777-2514

Testimony of the CDC Coalition

Concerning the Centers for Disease Control and Prevention's Budget for Fiscal Year 2011
 House Appropriations Subcommittee on Labor, Health and Human Services and Education
 Submitted for the Record, April 16, 2010

The CDC Coalition is a nonpartisan coalition of more than 100 groups committed to strengthening our nation's prevention programs. Our mission is to ensure that health promotion and disease prevention are given top priority in federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs. Coalition member groups represent millions of public health workers, clinicians, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency – not just the individual programs that it funds. In the best judgment of the CDC Coalition – given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases, increasing drug resistance to critically important antimicrobial drugs and our many unmet public health needs and missed prevention opportunities – **we believe the agency will require funding of at least \$8.8 billion for CDC's "core programs"**

We appreciate the Subcommittee's work over the years, including your recognition of the need to fund chronic disease prevention, infectious disease prevention and treatment, and environmental health programs at CDC. We also appreciate the support you provided in the economic recovery legislation for public health and prevention and wellness funding. By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. Ensuring a strong CDC is especially important given the important role CDC will play as the nation moves forward with implementing the strong public health and prevention provisions contained in the historic health reform legislation recently signed by President Obama.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak. This has been demonstrated most recently by CDC's quick response and ongoing investigation into human infections with H1N1 flu (swine flu) in the United States and internationally.

Unfortunately, the president's budget proposal would actually cut CDC's core programs by more than \$130 million from the FY 2010 enacted level. We must make up the lost ground and fully fund CDC's core public health programs at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or

accountability. Until we are committed to a strong public health system, every crisis will force trade offs.

The Multiple Roles of CDC

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for state and local capacity grants. We ask the Subcommittee to ensure that our states and local communities can be prepared in the event of an act of terrorism or other public health threat this year and in future years. Unfortunately, this is not a threat that is going away.

Public health programs delivered at the state and local level should be flexible to respond to state and local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services (PHHS) Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from PHHS Block Grant programs is strong, yet so many requests go unfunded. We greatly appreciate the Subcommittee's past support for this program and we urge your continued support so that states can tailor federal public health dollars to meet their specific needs.

Addressing the Leading Causes of Death and Disability

Heart disease remains the nation's No. 1 killer. In 2007, nearly 616,000 people in the United States died from heart disease, accounting for nearly 25% of all U.S. deaths. Of those who died from heart disease, 50% were women. Stroke is the third leading cause of death and is a leading cause of disability. In 2007, stroke killed more than 134,000 people (60% of them women), accounting for about 1 of every 18 deaths. Currently only 31 states and the District of Columbia are funded, 27 as capacity building and only 14 as basic implementation through CDC's Heart Disease and Stroke Prevention Program. We must expand these efforts to continue the gains we have made in combating heart disease and stroke.

The CDC funds proven programs addressing cancer prevention, early detection, and care. Cancer is the second most common cause of death in the United States. In 2008, more than 1.4 million new cases of cancer will be diagnosed, and about 565,650 Americans – more than 1,500 people a day – are expected to die of the disease. The financial cost of cancer is also significant. According to the National Institutes of Health (NIH), in 2007 the overall cost for cancer in the United States was more than \$219 billion: \$89 billion for direct medical costs, \$18.2 billion for lost worker productivity due to illness, and \$112 billion for lost worker productivity due to premature death.

Among the ways CDC is fighting cancer, is through funding the National Breast and Cervical Cancer Early Detection Program that helps low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to states to develop Comprehensive Cancer Control (CCC) plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and implement specific cancer prevention and control activities customized to address each state's particular needs. CDC also funds programs to raise awareness about colorectal, prostate, lung, ovarian and skin cancers, and the National Program of Cancer Registries, a critical registry for tracking cancer trends in all 50 states.

Chronic Obstructive Pulmonary Disease (COPD) – which includes emphysema and chronic bronchitis – is the fourth leading cause of death in the U.S. More than 12 million U.S. adults have been diagnosed with COPD, but an equal number are believed to have the disease but have not yet been diagnosed. We ask the Subcommittee to support the development of a federal action plan to respond to COPD by providing a specific appropriation to the National Center for Chronic Disease Prevention and Health Promotion.

Although more than 23.6 million Americans have diabetes, nearly 6 million cases are undiagnosed. From 1980-2007, the number of people with diabetes in the United States more than quadrupled, from 5.8 million to 23.6 million. Each year, more than 20,000 people with diabetes become blind, more than 46,000 develop end-stage kidney disease, and about 71,000 have leg, foot, or toe amputations. Preventive care such as routine eye and foot examinations, self-monitoring of blood glucose, and glycemic control could reduce these numbers. Unfortunately funding for diabetes, along with many other core CDC programs, has either been cut or flat funded for the past several years. Without additional funds, most states will not be able to create programs based on these new data. States also will continue to need CDC funding for diabetes control programs that seek to reduce the complications associated with diabetes.

Over the last 25 years, obesity rates have doubled among adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The First Lady's *Let's Move!* campaign is bringing welcome attention to health promotion and obesity prevention. CDC funds programs to encourage the consumption of fruits and vegetables, to get sufficient exercise, and to develop other habits of healthy nutrition and activity. To fully support these activities, we urge the Subcommittee to provide adequate funding for the Division of Nutrition, Physical Activity and Obesity and the Healthy Communities Program.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit. We must continue to support these vital programs and reduce tobacco use in the United States.

Each day more than 3,900 young people initiate cigarette smoking. At the same time, according to CDC, only 3.8% of elementary schools, 7.9% of middle schools and 2.1% of high schools provide daily physical education or its equivalent for the entire school year. Less than ten percent of schools require daily physical education. Almost 90% of young people do not eat the recommended number of servings of fruits and vegetables, while nearly 30% of young people are overweight or at risk of becoming overweight. And every year, almost 800,000 adolescents become pregnant and nearly 4 million teens are infected with a sexually transmitted disease. School health programs, funded through CDC's Division of Adolescent and School Health, are one of the most efficient means of correcting these problems, shaping our nation's future health, education, and social well-being.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV, 21 percent of who are unaware of their infection. Also, the number of people living with HIV is increasing, as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic that has already killed over 550,000 in the U.S. and is devastating populations around the globe. CDC's HIV prevention efforts must be expanded.

The United States has the highest rates of sexually transmitted diseases (STDs) in the industrialized world. More than 19 million new infections occur each year, almost half of them among young people. CDC estimates that STDs, including HIV, cost the U.S. healthcare system as much as \$15.3 billion annually. Over the past several years, significant ground has been lost in the fight against STDs. While syphilis was on the verge of elimination in the U.S. at the start of the decade, rates have increased by 114% since 2000. An adequate investment in STD prevention could save millions in annual health care costs in the future. Untreated STDs contribute to infant mortality, infertility, cervical cancer and an increased risk of HIV transmission. State and local STD control programs depend heavily on CDC funding for their operational support.

CDC and its National Center for Health Statistics (NCHS) collects data on chronic disease prevalence, health care disparities, emergency room use, teen pregnancy, infant mortality, causes of death, and rates of insurance to name a few. The health data collected through The Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey (NHANES) are an essential part of the nation's statistical and public health infrastructure. Adequate funding for these activities is essential for tracking America's health as a nation and developing targeted and appropriate public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's Racial and Ethnic Approaches to Community Health (REACH), is helping states address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. Our members are committed to ending the disparities and we encourage the Subcommittee to provide adequate funds for CDC's REACH program.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. The value of adult immunization programs to improve length and quality of life, and to save health care costs, is realized through a number of CDC programs, but there is much work to be done and a need for sound funding to achieve our goals. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination and significant racial and ethnic disparities in vaccination levels persist among the elderly. In addition, developing functional immunization registries in all states will be less costly in the long run than maintaining the incomplete systems currently in place.

Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on seven vaccines recommended in the childhood series, \$16.50 is saved in direct and indirect costs. An estimated 14 million cases of childhood disease and 33,000 deaths are prevented each year through timely immunization. Despite the incredible success of the program, it faces serious financial challenges. We thank the Subcommittee for its support for including Section 317 funds in the Recovery Act and we ask that you work to fully fund the program in order to cover all who are currently underserved by the program.

Injuries are the leading causes of death for persons aged 1-44 years. Unintentional injuries and violence such as older adult falls, unintentional drug poisonings, child maltreatment and sexual violence accounts for over 35% of emergency department visits annually with nearly 30 million people being treated in U.S. emergency departments each year. Annually, injury and violence ultimately cost the United States approximately \$406 billion in direct and indirect medical costs

including lost productivity. Furthermore, unintentional injury consistently remains the leading cause of death among young Americans ages 1-34 with 37.1 percent of unintentional fatal injuries caused by motor vehicle traffic fatalities. Conversely, violence related injuries are also substantial with homicide being the second leading cause of death for persons 15-24 years, while suicide is the 11th leading cause of death across all age groups. The consequences of these injuries can be far reaching from physical, emotional, financial turmoil to long term disability. Though these facts paint a grim picture, current research shows that injuries are entirely preventable.

CDC's Injury Center works to prevent unintentional and violence-related injuries to minimize the consequences of injuries when they occur by researching the problem; identifying the risk and protective factors; developing and testing interventions; and ensuring widespread adoption of proven strategies. We urge you to include increased funding for CDC's injury programs.

Of the four million babies born each year in the United States, one in every 33 is born with one or more birth defects. Birth defects are the leading cause of infant mortality, accounting for more than 20% of all infant deaths. Children with birth defects who survive often experience lifelong physical and mental disabilities. An estimated 40 to 50 million people in the U.S currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. Direct and indirect costs associated with disability exceed \$300 billion.

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities. We urge the Committee's continued support for these vital programs.

We also encourage the Subcommittee to provide adequate funding for CDC's Center for Environmental Health to revitalize environmental public health services at the national, state and local level. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, E. coli and lead in drinking water. We support additional funding for CDC's Environmental Health Laboratory and the National Environmental Public Health Tracking Program. We thank the Subcommittee and ask you to continue your recent efforts to expand and enhance CDC's capacity to help the nation prepare for and adapt to the health effects of climate change. Expanded funding would allow CDC to: establish a research coordinating center to coordinate a work group on climate change and health research; create a federal Interagency Task Force on Climate Change and Health to assess the public health implications of major climate, energy, transportation and agricultural policies; develop preparedness strategies for climate change tailored to local needs; and fund academic "Centers of Excellence" at universities to conduct climate change and health research.

We appreciate the Subcommittee's hard work in advocating for CDC programs in a climate of competing priorities. We thank you for considering our **FY 2011 request for \$8.8 billion for CDC's "core programs."**

**TESTIMONY OF KEITH NORRIS, M.D., FACP
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PRESENTED BEFORE THE

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND
HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**

APRIL 12, 2010

SUMMARY OF FISCAL YEAR 2011 RECOMMENDATIONS:

- 1) **\$300 MILLION FOR THE HEALTH RESOURCES AND SERVICES ADMINISTRATION TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS, INCLUDING:**
 - **\$33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE**
 - **\$35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**
- 2) **PROVIDE AN INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH (NIH), SPECIFICALLY:**
 - **\$500 MILLION FOR THE NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES (NCMHD)**
 - **SUPPORT THE NATIONAL CENTER FOR RESEARCH RESOURCES:**
 - **PROPORTIONAL INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS**
 - **\$119 MILLION FOR EXTRAMURAL FACILITIES CONSTRUCTION.**
- 3) **\$65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH**
- 4) **\$65 MILLION FOR THE DEPARTMENT OF EDUCATION'S STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS PROGRAM.**

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to present you with testimony. The Charles Drew University is distinctive in being the only dually designated Historically Black Graduate Institution and Hispanic Serving Institution in the nation. We would like to thank you, Mr. Chairman, for the support that this subcommittee has given to our University to produce minority health professionals to eliminate health disparities as well as do groundbreaking research to save lives.

The Charles Drew University is located in the Watts-Willowbrook area of South Los Angeles. Its mission is to prepare predominantly minority doctors and other health professionals to care for underserved communities with compassion and excellence through education, clinical care, outreach, pipeline programs and advanced research that makes a rapid difference in clinical practice. The Charles Drew University has established a national reputation for translational research that addresses the health disparities and social issues that strike hardest and deepest among urban and minority populations.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Title VII Health Professions Training Programs: The health professions training programs administered by the Health Resources and Services Administration (HRSA) are the only federal initiatives designed to address the longstanding under representation of minorities in health careers. HRSA's own report, "The Rationale for Diversity in the Health Professions: A Review of the Evidence," found that minority health professionals disproportionately serve minority and other medically underserved populations, minority populations tend to receive better care from practitioners of their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health professions institutions, they are significantly more likely to: 1) serve in medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.

Minority Centers of Excellence: The purpose of the COE program is to assist schools, like Charles Drew University, that train minority health professionals, by supporting programs of excellence. The COE program focuses on improving student recruitment and performance; improving curricula and cultural competence of graduates; facilitating faculty and student research on minority health issues; and training students to provide health services to minority individuals by providing clinical teaching at community-based health facilities. For FY11, the funding level for COE should be \$33.6 million.

Health Careers Opportunity Program: Grants made to health professions schools and educational entities under HCOP enhance the ability of individuals from disadvantaged backgrounds to improve their competitiveness to enter and graduate from health professions schools. HCOP funds activities that are designed to develop a more competitive applicant pool through partnerships with institutions of higher education, school districts, and other community based entities. HCOP also provides for mentoring, counseling, primary care exposure activities, and information regarding careers in a

primary care discipline. Sources of financial aid are provided to students as well as assistance in entering into health professions schools. For FY11, the HCOP funding level of \$35.6 million is suggested.

NATIONAL INSTITUTES OF HEALTH'S CONTRIBUTION TO FIGHTING HEALTH DISPARITIES

National Institute on Minority Health and Health Disparities: The NIMHD is charged with addressing the longstanding health status gap between under-represented minority and non minority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, telemedicine technology and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and developed a comprehensive plan for research on minority health at NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the COE program and HCOP. *For FY11, \$500 million is recommended for NIMHD to support these critical activities.*

Research Centers At Minority Institutions

RCMI at the National Center for Research Resources (NCRR) has a long and distinguished record of helping institutions like The Charles Drew University develop the research infrastructure necessary to be leaders in the area of translational research focused on reducing health disparities research. Although NIH has received some budget increases over the last five years, funding for the RCMI program has not increased by the same rate. *Therefore, the funding for this important program grow at the same rate as NIH overall in FY11.*

Extramural Facilities Construction

Mr. Chairman, one issue that sets The Charles Drew University and many minority-dedicated institutions apart from the major universities of this country is the facilities where research takes place. The need for research infrastructure at our nation's minority serving institutions must also remain strong to maximize efforts to reduce health disparities. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources (NCRR) is \$250 million. The law also includes a 25% set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to \$50 million. In FY11, we respectfully request.

DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH

Specific programs at OMH include: assisting medically underserved communities, supporting conferences for high school and undergraduate students to interest them in health careers, and supporting cooperative agreements with minority institutions for the

purpose of strengthening their capacity to train more minorities in the health professions. *For FY11, I recommend a funding level of \$75 million for OMH to support these critical activities.*

STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS - DEPARTMENT OF EDUCATION: The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. *In FY11, an appropriation of \$75 million is suggested to continue the vital support that this program provides to historically black graduate institutions.*

CONCLUSION

Despite all the knowledge that exists about racial/ethnic, socio-cultural and gender-based disparities in health outcomes, the gap continues to widen. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventative care and research are inaccessible either due to distance or lack of facilities and expertise. As noted earlier, in just one underserved area, South Los Angeles, the number and distribution of beds, doctors, nurses and other health professionals are as parlous as they were at the time of the Watts Rebellion, after which the McCone Commission attributed the so-named 'Los Angeles Riots' to poor services - particularly access to affordable, quality healthcare. The Charles Drew University has proven that it can produce excellent health professionals who 'get' the mission - years after graduation they remain committed to serving people in the most need. But, the university needs investment and committed increased support from federal, state and local governments and is actively seeking foundation, philanthropic and corporate support.

Even though institutions like The Charles Drew University are ideally situated (by location, population, community linkages and mission) to study conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, the Life Sciences Research Facility will translate insight gained through research into greater understanding of disparities and improved clinical outcomes. Additionally, programs like Title VII Health Professions Training programs will help strengthen and staff facilities like our Life Sciences Research Facility.

We look forward to working with you to lessen the huge negative impact of health disparities on our nation's increasingly diverse populations, the economy and the whole American community.

Mr. Chairman, thank you again for the opportunity to present testimony on behalf of The Charles Drew University. It is indeed an honor.

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Dear Members of the House Appropriations Committee:

I would like to take this opportunity to speak up against the idea of any type of user fee-based certification for the Voluntary Protection Programs (VPP). As an employee at a VPP site, I believe that this will severely diminish the integrity of the VPP program and the culture of which has defined the VPP program over the past 26 years.

In his report to the House Budget Committee on March 4, 2010, Congressman George Miller (D-CA), chair of the House Committee on Education and Labor, supported the Department of Labor's (DOL) shift of funding and resources away from VPP in favor of enforcement. He proposed to fund VPP "*through a user fee, and plans to work on establishing authority for augmenting the OSHA budget through a fee based system*". Funding VPP through a user-fee system for certification would take away the independent verification of our safety and health management system because it would lead to a direct relationship between number of VPP sites and fees paid to the government. Some repeated concerns which have been expressed by many of our 921,000 American workers now covered by VPP program include:

- Industry directly funding the government to perform part of its required function under the OSH Act.
- Creating the perception that employers are "buying" the VPP flag.
- Creating a situation where employers can be perceived as purchasing "an exemption from routine OSHA inspections."
- Fees for VPP deterring small businesses from participating.
- Charging sites for participation in VPP despite of what VPP sites voluntarily give in the form of mentoring, outreach, assist visits, funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national conferences.
- Paying a fee reduces VPP to a mere government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride that has been in place for the past 26 years.

By implementing this type of a user fee system worksites would be directly funding the Occupational Safety and Health Administration (OSHA) to perform their functions as required by the OSH Act. The Occupational Safety and Health Act of 1970, requires 13 objectives to be accomplished. Only **one** of those 13 objectives is enforcement, **two** are standard settings, and **three** are directly related to the development of cooperation between employer and employee to establish a safe workplace – exactly what the founders of OSHA VPP established the program to

accomplish. Congress and DOL taking actions to shift funding from VPP in favor of enforcement is not a return to OSHA's 'roots in enforcement,' only an Agency that is ignoring 12 other mandates from Congress and asking American's worksites to "pay to play" would provide the funding through a user fee-based system and require each worksite to pay the agency to implement all the requirements under the OSH Act.

Unlike many fee-based certification programs, VPP is a comprehensive workplace safety and health management system that is built on cooperation among workers, employers and government. If the DOL backs away from the partnership, it greatly diminishes the program instead of strengthening OSHA's partnership with corporate America in an effort to push beyond outdated standards.

I am a firm believer in firm and fair enforcement for those worksites that put their employees in harms way and refusing to implement safety and health programs that would protect the workers. It is clear that 40 years of enforcement have left American's small businesses - collectively the largest employers and source of future "good jobs" - severely lacking. Under this and previous administrations, OSHA's dealings with America's small businesses has either developed a 'hands-off' attitude or "fine and penalized these small businesses to closure or forced them to take their business out of the country," because these are the options in an Agency focusing solely on enforcement. In recent years, smaller worksites have increased significantly within VPP, growing from 28 percent of VPP sites in 2003 to 39 percent in 2008, thanks to innovations such as VPP Mentoring and the VPP Challenge Program. Innovations such as these are keeping employees safer at worksites that traditionally would not see an OSHA compliance inspection or, if fined, might have to go out of business or at the very least provide lay-off notices to employees to cover the citation and associated fines and penalties. Many of these worksites have seen the value in a proactive safety program, such as VPP, saving companies and taxpayers money. Companies along with their employees who have seen the benefits of VPP are mentoring those to achieve this exemplary distinction.

In 2007, OSHA evaluated the benefits of the VPP and reported that Federal Agency VPP participants, in OSHA, the Department of Energy (DOE), the Department of Defense (DOD), and the National Parks Service, to name a few, saved the government more than \$59 million by avoiding injuries and the private sector VPP participants saved more than \$300 million. These funds are a return on investment that are funneled into new equipment, expanding production, creating 'good jobs,' keeping 'good jobs,' and voluntarily mentoring other work sites in the community to learn the value of VPP and keeping American workers safe. That money should not be used to fund the Federal Government to perform its required obligations under the OSH Act.

The Federal Government already benefits from its involvement in VPP and from the private sector's participation in VPP, such as:

- The \$59 million saved by Federal Agency participants in VPP is money that demonstrates fiscal responsibility and cost avoidance and allows for the reallocation of resources to the mission of the Agency.

- The U.S. Department of Labor's Safety, Health, and Return-to-Employment (SHARE) initiative was launched in 2004 to help the Federal Government in reducing injury and illness cases and lost production day rates, and to substantially improve timely filing of injury and illness notices. Agencies that adopted VPP achieved greater and sustainable improved performance in the SHARE initiative and want to expand the VPP throughout their operations.
- The DOD, with 31 VPP sites, has seen a substantial return on investment by adopting VPP in terms of reduced injuries and illnesses and a strong improvement in maintaining mission-readiness.
- In 2003, the DOE Appropriations language noted a dramatic improvement in the safety and health within the Complex and challenged DOE to "*maintain worker safety and health performance at least to levels seen in 2002,*" that performance was achieved by 21 VPP sites in the DOE Complex.
- The cost avoidance in workers compensation for a single contractor in the DOE Complex was a \$3 million cost reduction in three years by working toward and installing VPP. That was \$3 million in taxpayers' money redirected to the DOE mission, just by preventing worker injuries.
- OSHA also directly benefits by reducing employee injuries and illnesses at three of its Regional Field Offices that are VPP.
- Additionally, when workplaces make the significant commitment to safety required by VPP, it allows OSHA to focus its resources of enforcement where they are most needed – on those companies that "*don't get it*" – as stated by the Secretary of Labor.

Recent tragic events in the American workplace cause us great concern, such as the mining disaster in West Virginia and the refinery explosion in Washington state. These events remind us that when we continue to return to only one tool in OSHA's toolbox to achieve a safe workplace – and that tool is enforcement – that we will never achieve, as a nation, the necessary culture, mindset and attributes necessary to protect our most valued asset – the American worker. Each of these tragic examples, worksites and employers had received routine inspections and citations from OSHA and the Mine Safety & Health Administration (MSHA) compliance officers. Those visits were routine, on average five inspections in the past seven years, all with citations and large fines. These events demonstrate what 40 years of enforcement have achieved; and why would recapitulating this lesson return different results? Would more workers go home to their families at night?

Instead, "*What if*" just one of those OSHA or MSHA inspections the compliance officer would have recommended the company enter into the VPP Challenge Program?

- *What if*, through OSHA's VPP, one of those companies had learned the value, in human preservation and financially, of preventing accidents and avoiding costs and impacts to the bottom line?
- *What if* one of those companies was the first in their industry to demonstrate that safety and profitability are achievable together?
- *What if* others in their industry took notice and started to embrace the same ideas and sought to achieve VPP status in order to maintain a competitive edge?

- *What if* a company never had to tell another loved one "I am sorry" there has been a serious accident.

Let's take away the "*What if*" and send workers home to their loved one each and night?

I am personally asking you to speak out against the idea of a fee-based Voluntary Protection Program and ensure the continued success of OSHA's VPP as a cooperative program by reinstating direct and continued funding in the DOL budget. Highly successful cooperative programs like VPP which have a proven track record for the past 26 years should be funded and expanded if OSHA is to assist American businesses in achieving the necessary cultural change required to maintain and protect American workers.

I am also personally asking that you provide full funding in the DOL budget for VPP and include specific Appropriations language to restore and direct the Agency to fund, resource load and conduct VPP assistance, application evaluations, onsite re-approvals and new onsite evaluations to the levels equal to or greater than those achieved in 2005.

Sincerely,

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**Testimony Of
TIMOTHY S. DAVIS
PRESIDENT AND CEO
CLOSE UP FOUNDATION
Before the
HOUSE APPROPRIATIONS
SUBCOMMITTEE on
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION and
RELATED AGENCIES
Contact: seth.maiman@closeup.org, 703/706-3478
April 16, 2010**

Mr. Chairman, my name is Timothy S. Davis, President and CEO of the Close Up Foundation and I submit this testimony in support of our \$5 million appropriations request for the Close Up Fellowship Program that is funded through a grant from the Department of Education, Office of Innovation and Improvement.

Close Up Foundation is a nonprofit, nonpartisan civic education organization dedicated to the idea that, within a democracy, informed, active citizens are essential to a responsive government. Close Up's mission is to inform, inspire, and empower students and their teachers to exercise their rights and accept the responsibilities of citizens in a democracy. Close Up's experiential methodology emphasizes that democracy is not a spectator sport, and provides young people with the knowledge and skills to participate in the democratic process.

Close Up fulfills its mission with exciting, hands-on programs for students and their teachers in Washington. Close Up uses the city as a living classroom, giving students unique access to the people, processes and places that make up our nation's capital. Our students are a diverse group – coming from every state and beyond and from all walks of life. Over 650,000 have graduated from our experiential programs.

Three core principles of Close Up are: 1) family income should not be a barrier to a student's participation, 2) commitment to diversity – outreach should reach a broad cross section of young people, and 3) enrollment should be open to all students, not just student leaders or high academic achievers.

The Close Up Fellowship Program provides for financial assistance to economically disadvantaged students and their teachers to participate on week-long Close Up Washington civic education programs. The Fellowship Program, authorized in federal law since 1972 and currently under Section 1504 of the No Child Left Behind Act, has been annually funded through a U.S. Department of Education grant for over thirty-five years. The program provides financial assistance to economically disadvantaged high school and middle schools students and their teachers. Close Up

makes every effort to ensure the participation of students from rural, small town and urban areas and gives special consideration to students with special educational needs, including students with disabilities, ethnic minority students, and students with migrant parents. Student fellowship recipients are selected by their schools and must qualify according to the income eligibility guidelines established by Close Up.

Close Up Fellowship Program recipients participate in Close Up Washington civic education programs with all other Close Up participants. Student fellowship recipients participate in the Washington High School Program, the Washington Middle School, and the Program for New Americans. There is no special programming for Fellowship recipients nor are they identified or singled out in any manner. Fellowship recipients add diversity to the student body on Close Up programs. The fellowship program thus benefits not only the recipient but all Close Up student program participants.

Close Up provides a federal fellowship to a select group of teachers who work with economically disadvantaged students on a Close Up program. Close Up teachers participate in the Close Up Program for Educators, a program which “trains the trainers”. Teachers take ideas and methodologies for teaching and engaging young people in civic activities and put them to use in their schools and communities.

The teacher is the essential link to reaching students of diverse backgrounds. Close Up believes that any effort to improve and promote civic involvement among young people must begin with inspired and well-prepared teachers. It is from this inspired corps of teachers that a multiplier effect in civic learning and engagement is produced. Teachers who participate in the teacher program leave inspired and informed and convey a similar attitude to their students. In a survey of teachers who participated on the Close Up Program for Educators in spring 2009, 95% of the teachers who responded indicated that they returned to their schools feeling “inspired and reinvigorated” after completing the Close Up program.

Close Up is grateful to the United States Congress for its long-standing support of the Close Up Fellowship Program through the appropriations process. Tens of thousands of young people have been able to participate on Close Up Washington civic education programs as a result of the federal funding.

Close Up’s FY11 request is based its desire to significantly increase the number of economically disadvantaged young people who participate on Close Up Washington civic education programs. The funds, which assist the disadvantaged and provide seed money for at-risk schools and communities to participate on these life transforming programs, are more important now than ever. Given the economic climate it has become even more challenging for communities to raise the necessary funds for participation on Close Up programs. The federal funding bridges that gap and Close Up feels that with aggressive outreach into economically distressed communities we can continue to provide these experiences to our young people.

Close Up civic education programs also helps to fill a gaping hole in the civic education of our nation's youth. In a recent survey of high school teachers, 83% reported that emphasis on standardized tests has made it difficult to teach practical citizenship skills in the classrooms. As the teaching of social studies and civics has given way to STEM subjects, programs like Close Up become an even more important as a supplement to classroom teaching.

Close Up's appropriations request reflects the increasing cost of providing these important Washington programs. The cost of airfare, accommodations, food and local transportation skyrocketed during the decade the Close Up Fellowship funding remained flat at under \$1.5 million. The increase in the appropriations amount to \$1.942 million in FY08 has helped combat a small portion of those increased costs but still results in a sharp decrease in the number of economically disadvantaged students that Close Up has been able to serve. We believe that during hard economic times it is even more imperative for the federal government to invest in the civic education of young people. And, by investing in a Close Up education, the government also greatly supports economic sectors such as transportation and hospitality which are suffering in the downturn.

Members of Congress have the opportunity to meet with Close Up groups from their districts during Close Up "Capitol Hill Day". You see the excitement and pride as our students gain confidence to express their views on the public policy issues that most directly affect their lives. Through their workshops, seminars and experience of being in Washington, Close Up instills these students with the knowledge and skills to become active citizens in our democracy.

Many of your constituents would not be able to participate in this life altering program without the benefit of the Close Up Fellowship Program. There is no better investment that we can make in our nation's future than in building educated and responsible citizens, one person at a time.

Close Up respectfully requests that the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Services appropriate \$5 million for the Close Up Fellowship Program.

COALITION
FOR HEALTH SERVICES RESEARCH

W. David Helms, Ph.D.
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The Coalition for Health Services Research is pleased to offer this testimony regarding the role of health services research in improving our nation's health. The Coalition's mission is to support research that leads to accessible, affordable, high-quality health care. As the advocacy arm of AcademyHealth, the Coalition represents the interests of 3,800 researchers, scientists, and policy experts and 150 organizations that produce and use health services research.

Health care in the United States has the potential to dramatically improve people's health but often falls short and costs too much. Health services research is used to understand how better to finance the costs of care, measure and improve the quality of care, and improve coverage and access to affordable services. It provides patients, providers, payers, and policymakers with the tools needed to make health care:

- **Affordable** by decreasing cost growth to sustainable levels
- **Efficient** by decreasing waste and overpayment and monitoring the cost-effectiveness of care
- **Safe** by decreasing preventable medical errors, monitoring public health, and improving preparedness
- **Effective** by evaluating programs and outcomes and promoting evidence-based innovations
- **Equitable** by eliminating disparities in health and health care
- **Accessible**, by connecting people with the health care they need when they need it
- **Patient-centered** by increasing patient engagement in and satisfaction with the care received

Indeed, health services research has been changing the face of U.S. health care, uncovering critical challenges confronting our nation's health care system. For example, the 2000 Institute of Medicine (IOM) report *To Err Is Human* found that up to 98,000 Americans die each year from medical errors in the hospital. Health services research also found that disparities and lack of access to care in rural and inner cities result in poorer health outcomes. And it demonstrated that obesity accounts for more than \$92 billion in medical expenditures each year and has worse effects on chronic conditions than smoking or problem drinking.

But health services research does not just lift the veil on the problems plaguing U.S. health care; it also seeks ways to address them. Health services research offers guidance on implementing and making the best use of health information technology and getting the best care at the best value. Health services research framed the debate over health care reform in Massachusetts—forming the basis for that state's 2006 health reform legislation—and was instrumental in shaping comprehensive national health reform through The Patient Protection and Affordable Care Act. As health reform is implemented over the next few years, health services research will be needed more than ever to monitor and evaluate the new law's impact on the health care system and the health status of Americans. Do Americans have better access to health care? Are the measures projected to bend the health care cost curve downward having the desired effect?

Are patients more engaged in health care decision-making? Is care better coordinated across providers? Health services research will provide the answers to these and other important questions.

For the last seven years, the Coalition has collected data to track the federal government's expenditures for health services research and health data. Information provided to us by the principal funders of health services research and data—including the Agency for Healthcare Research and Quality (AHRQ), the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Centers for Medicare and Medicaid Services (CMS)—indicates that the field of health services research and data has operated with diminished purchasing power for years. Up until 2008, overall spending on health care continued to rise faster than the rate of inflation—from \$1.4 trillion in 2000 to nearly \$2.3 trillion in 2008.ⁱ Despite the recent increase in federal funding for health services research and data—\$1.8 billion in FY 2009—the total federal investment still accounted for only 0.078 percent of the \$2.3 trillion we spend on health care annually.ⁱⁱ

The Coalition for Health Services Research greatly appreciates the subcommittee's recent efforts to increase the federal investment in health services research and comparative effectiveness research through the FY 2010 Omnibus Appropriations Act and the American Recovery and Reinvestment Act of 2009. This funding provides a new high watermark for the field and represents the largest-ever single funding increase in health services research. With comprehensive health reform now a reality, we ask the subcommittee to continue strengthening the capacity of the health services research field to address the pressing challenges America faces in providing access to high-quality, cost-effective care for all its citizens.

Agency for Healthcare Research and Quality

AHRQ is the lead federal agency charged with supporting unbiased, scientific research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. Recent years' steady, incremental increases for AHRQ's Effective Health Care Program, as well as the \$300 million provided to AHRQ in the American Recovery and Reinvestment Act, have helped AHRQ generate more comparative effectiveness research and expand the infrastructure needed to increase capacity to produce this evidence. However, funding for AHRQ's broader health services research portfolio has languished as funding for AHRQ's base has remained relatively flat. To balance the recent investments in AHRQ's comparative effectiveness research, we recommend that:

- AHRQ's broader health services research portfolio should not be sacrificed for the sole benefit of comparative effectiveness research. The entirety of the president's requested budget increase will support "patient-centered health research" (i.e., comparative effectiveness research) while funding for programs in AHRQ's broader research portfolio such as the Centers for Education and Research on Therapeutics and the HIV Research Network are cut or flat-funded to support a more robust comparative effectiveness research portfolio. The Coalition requests increased investment in other important research topics to balance continuing investments in comparative effectiveness research, as this research alone will not solve our health system challenges; the full spectrum of health services research on health care cost, quality, and access is essential to ensure that

research on “what works” is implemented in ways that support broader health reform efforts.

- Congress should continue to place priority on investigator-initiated research and should target funding for innovative, competitive grants in FY 2011. The principle of scientific competition and innovation is the basis for allocating the large share of research funding managed by the NIH. Yet, the president’s proposed budget does not fund new investigator-initiated research grants at AHRQ in FY 2011. The Coalition is grateful to the subcommittee for its leadership in recognizing the value of competitive scientific discovery and innovation in health services research, as demonstrated by the priority you have placed on investigator-initiated research at AHRQ. The Coalition requests that you continue this investment in FY 2011 and sustain the momentum for competition and innovation you have cultivated over several years.
- Congress should target more funding for pre- and post-doctoral training grants to increase capacity to respond to growing public and private sector demand for health services research. At the direction of Congress, AHRQ doubled its investment in training grants for the next generation of researchers in the last year—from \$5.4 million for 40 grants in FY 2009 to \$12.7 million for 79 grants in FY 2010. Despite this significant increase, the Coalition believes that such a level of investment in training grants for new researchers falls far short of what is needed across all disciplines to meet growing public and private sector demand for health services research. As the lead agency for health services research, AHRQ requires funding to develop the next generation of health services researchers—both physician and non-physician researchers.

While targeted funding increases in recent years have moved AHRQ in the right direction, more core funding is needed to help AHRQ fulfill all aspects of its mission. We join the Friends of AHRQ—a coalition of more than 250 health professional, research, consumer, and employer organizations that support the agency—in supporting the president’s requested funding level of \$611 million.

Centers for Disease Control and Prevention

Housed within the CDC, the National Center for Health Statistics (NCHS) is the nation’s principal health statistics agency, providing critical data on all aspects of our health care system. Thanks to NCHS, we know that too many Americans are overweight and obese, that cancer deaths have decreased, that average life expectancy has increased, and that emergency rooms are over-crowded. We also know how many people are uninsured, how many children are immunized, how many Americans are living with HIV/AIDS, and how many teens give birth.

With the subcommittee’s leadership in securing steady and sustained funding increases for NCHS over the last three fiscal years, NCHS is rebuilding after years of underinvestment that forced the elimination of data collection and quality control efforts, threatened the collection of vital statistics, stymied the adoption of electronic systems, and limited the agency’s ability to modernize surveys to reflect changes in demography, geography, and health delivery. We join the Friends of NCHS—a coalition of more than 250 health professional, research, consumer, industry, and employer organizations that support the agency—in endorsing the president’s FY

2011 request of \$162 million, a funding level that will build on your previous investments and put the agency on track to become a fully functioning, 21st Century, national statistical agency.

While significant funding has helped improve the public health system's capacity to respond to a terrorist attack or a public health crisis such as pandemic flu, funding has been insufficient to support research that evaluates the effectiveness of our preparedness interventions and seeks to improve the delivery of public health services. For example, how cost-effective are public health and prevention programs? How can the medical care and public health delivery systems be better linked?

The Patient Protection and Affordable Care Act recognizes the need for linking the medical care and public health delivery systems by authorizing a **new CDC research program to study the delivery of public health services**. If funded in FY 2011, this program will support the examination of evidence-based practices relating to prevention; analyze the translation of interventions from academic to real-world settings; and identify effective strategies for organizing, financing, or delivering public health services in real-world community settings by, for example, comparing state and local health department structures and systems in terms of effectiveness and costs. The Coalition urges you to appropriate \$50 million for this important program in FY 2011, enabling us to study ways to improve the efficiency and effectiveness of public health service delivery.

In addition, the Coalition urges you to provide the CDC's important **Public Health Research** portfolio and **Prevention Research Centers**—a network of academic health centers that conduct public health research—with at least \$35 million for Public Health Research and at least \$35 million for Prevention Research Centers in FY 2011. These programs—which seek ways to develop, translate, and disseminate research to address obesity, diabetes, and heart disease; healthy aging and youth development; cancer risk; and health disparities—have been virtually flat-funded since FY 2006. At a time when chronic diseases persist as the primary drivers of escalating health care costs, greater investment in public health research is needed to identify evidence-based solutions to curbing the prevalence of these diseases.

Centers for Medicare and Medicaid Services

Steady funding decreases for the Office of Research, Development and Information, together with an increasingly earmarked budget, have hindered CMS's ability to meet its statutory requirements and conduct new research to strengthen public insurance programs—including Medicare, Medicaid, and the Children's Health Insurance Program—which together cover nearly 100 million Americans and comprise 45 percent of America's total health expenditures.ⁱⁱⁱ As these federal entitlement programs continue to pose significant budget challenges for both federal and state governments, it is critical that we adequately fund research to evaluate the programs' efficiency and effectiveness and seek ways to manage their projected spending growth.

The Coalition supports an increase in CMS's discretionary research and development budget from \$36 in FY 2010 to a base FY 2011 funding level of \$47 million, consistent with the president's request. This funding is a critical down payment to help CMS recover lost resources and restore research to evaluate its programs, analyze pay for performance and other tools for

updating payment methodologies, and further refine service delivery methods.

In addition, the Coalition supports the president's FY 2011 request of \$110 million for a new data improvement initiative at CMS. This initiative has the potential to transform CMS's data infrastructure from one designed to support claims processing to one that better supports research and analysis. Specifically, this investment would enhance the quality and timeliness of data, support health reform initiatives such as value-based purchasing and comparative effectiveness research, improve payment accuracy, and enhance systems security. The Coalition supports the president's efforts to improve data quality, timeliness, and access and encourages Congress to appropriate funding so that the research community will be able to access CMS's valuable data to enhance these federal programs and ultimately reduce mandatory spending.

National Institutes of Health

NIH reported that it spent \$1.1 billion on health services research in FY 2009—roughly 3.6 percent of its entire budget—making it the largest federal sponsor of health services research. For FY 2011, the Coalition recommends a health services research base funding level of at least \$1.27 billion—3.6 percent of the \$35 billion sought by the broader health community for NIH. The Coalition believes that NIH should increase the proportion of its overall funding that goes to health services research from 3.6 to 5 percent to ensure that discoveries from clinical trials are effectively translated into health services. We also encourage NIH to foster greater coordination of its health services research investment across its institutes.

In conclusion, the accomplishments of health services research would not be possible without the leadership and support of this subcommittee. As you know, the best health care decisions are based on relevant data and scientific evidence. With important health reforms now undergoing implementation, health services research will continue to yield valuable scientific evidence in support of improved quality, accessibility, and affordability of health care. We urge the subcommittee to accept our FY 2011 funding recommendations for the federal agencies funding health services research and health data.

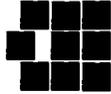
If you have questions or comments about this testimony, please contact our Washington, D.C., representative Emily Holubowich at 202.484.1100 or eholubowich@dc-crd.com.

¹ Hartman, M. et al. "National Health Spending in 2007: Slower Drug Spending Contributes to Lowest Rate of Overall Growth since 1998," *Health Affairs*, Vol. 28, No. 1, January/February 2009, pp. 246-61.

ⁱⁱ Coalition for Health Services Research. *Federal Funding for Health Services Research*, available at www.chsr.org, February 2009.

ⁱⁱⁱ Catlin, A. et al. "National Health Spending in 2005: The Slowdown Continues," *Health Affairs*, Vol. 26, No. 1, January/February, pp. 142-53.

Coalition for Heritable Disorders of Connective Tissue



IN PARTNERSHIP WITH THE AMERICAN ASSOCIATION OF MATRIX BIOLOGY

Testimony on behalf of the Coalition of Heritable Disorders of Connective Tissue (CHDCT)

February 17, 2010

Chairman Dave Obey, and Ranking Member, Todd Tiahrt, and members of the Subcommittee:

The Coalition of Heritable Disorders of Connective Tissue (CHDCT) thank you for the opportunity to submit testimony regarding the FY 2011 budget for the National Institutes of Health.

We, the member organizations of the CHDCT are learning, as we experience the aging of the Heritable Disorders of Connective Tissue (HDCT) population, just how limited the current surgical repairs and current therapies are in protecting the health of people with these disorders. We now have the perspective to see how affected people lose their quality of life through disability due to the incurable and progressive nature of the disorders, additional surgeries and treatments are needed. We see our long-time members dying after repeated surgery has reached its limit in repairing the human body. The aging of the HDCT population has demonstrated the limits of surgical intervention and current treatments and this urges us forward in developing new technologies and finding more aggressive approaches to healing the ravages of these “wayward” mutations. Still, too many young people are dying through lack of knowledgeable diagnosis, inadequate care, and a lack of the true understanding of the complexities of these disorders. All of which mitigates for increased long-range research of HDCT.

RECOMMENDATION: We commend the Committee for its understanding, and response to, the impact of the progressive degenerative nature of the diseases of connective tissue, concern regarding current surgery and treatments, and impact on the aging population and look for additional support of HDCT research..

We represent thousands of individuals living with heritable disorders of connective tissue with a coalition of 14 advocacy and support groups, which affect in total over a million people. Heritable disorders of connective tissue are rare diseases that result from mutations in genes responsible for building tissues. Basic statistical information about these disorders is difficult to come by and unreliable at best even though disorders of connective tissue may affect over one million people in the United States. Abundant information about genes and genotypes is critical, but it is difficult to apply this information to health until robust surveillance and epidemiological information is gathered.

As we have written in our coalition testimony to Congress, progress on the translation of basic science to treatments and therapies cannot be made without correlating genotype to phenotype. The patient support groups which are members of the Coalition of Heritable Disorders of Connective Tissue (CHDCT) realize the need to understand: the incidence and prevalence of these diseases, the characteristics of these diseases, and the longitudinal progress of those diseases in various populations.

RECOMMENDATION: We urge the Committee to support the need for reliable data mandates for a registry of heritable disorders of connective tissue designed to identify the similarities and differences of these HDCT disorders, thus facilitating the work of the researcher and providing essential data.

In the past ten years, in response to the Third Workshop on Heritable Disorders of Connective Tissue (HDCT) supported by the NIAMS, that was held at NIH in November, 2000, a number of grants on HDCT were funded. These grants supported individual research projects as well as collaborative exploratory and developmental grants that investigate the cause of one or more of these disorders and novel treatment pathways. As Dr. Stephen Katz, NIAMS Director, stated in the announcement of the grant awards: "We are pleased with the quality of research that has been proposed in response to the Request for Applications," adding, "We need to understand more about these disorders and how they can be effectively treated."

RECOMMENDATION: We thank the Committee and welcome the long range strategic plans which provide an opportunity to expand future programs in support of HDCT research already in place under the heading of the Cartilage and Connective Tissue Research program and endorsed in NIH and NIAMS long range strategic plans.

Among the recommendations of the 3rd HDCT workshop for future research directives and current research interests:

- Continued use of mouse models to elucidate the sequence of events in the pathogenesis of human connective tissue disorders;
- Structure, role and interactions of extra cellular matrix molecules both inside and outside the cell;
- Role of the extra cellular matrix in cell differentiation;
- Development of therapies for connective tissue regeneration with mesenchymal stem cells.
- Importance of certain enzymes for collagen synthesis
- Role of bone marrow transplantation

RECOMMENDATION: We urge the Committee to continue to address the recommendations of the 3rd Workshop on HDCT and current promising new developments.

There have been efforts to facilitate access to information and current research of disease both for the research community and for the patient organizations, such as the CHDCT. The CHDCT is compiling documentation in support of the inclusion of HDCT as a category in the NIH Research Portfolio Online Reporting Tool (RePort) system used to categorize disease. Located within the RePort, is the RCDC, which establishes subject/ categories of disease. RCDC stands for “Research, Condition, and Disease Categorization system,” and uses the categories for reporting NIH funded research, and areas of research. Currently the 215 categories, which are vitally important in providing access to this information, do not include HDCT. Therefore the category of “heritable disorders of connective tissue, (HDCT)” – which covers over 200 disorders – is a necessary category in order to expedite access by researchers to NIH funding in this area of study.

The National Institute of Health (NIH) has established the NIH RePorter, or research/condition/disease category (RCDC) which provides retrieval of information on scientific projects and studies. This excellent new tool provides information on research results, expediting access and the avoidance of duplication. But the disease group of HDCT is located under Connective Tissue Disease, and other difficult to locate subjects, which includes many unrelated to HDCT, therefore limiting the value of this important program for the research community and for the disease organizations represented within the HDCT group.

RECOMMENDATION: We commend the Committee for its support of the RePORT program, which is essential to provide coordinate access to research information on all disease groups. We also urge the inclusion of the disease group of heritable disorders of connective tissue in order to facilitate the exchange of information regarding research and the research community. At present it is difficult to track HDCT, since current RCDC key terms and concepts do not differentiate between the thousands of various connective tissue disease groups within the 215 terms of disease currently in use. The RePorter and specifically the RCDC programs should include the HDCT category of disorders as a subject heading. This subject heading is well documented as described in *McKusick's Heritable Disorders of Connective Tissue*, and the recently revised NIAMS informative brochure “*Questions and Answers: Heritable Disorders of Connective Tissue*,” and as such warrant its RCDC subject heading of “*Heritable Disorders of Connective Tissue*.”

The CHDCT has had a synergistic partnership with the American Society of Matrix Biology (ASMB). A number of conference presentations related to HDCTs have addressed subjects such as, “Fibrillin Microfibrils in Elastogenesis and Remodelling,” “Mice That Lack MAGP-1 Display Subtle Connective Tissue and Bleeding Abnormalities,” “Establishing Connective Tissue Pathways That Regulate Morphogenesis,” and “Latent TGF-Beta Binding Proteins Orchestrators of TGF-beta

Action.” Sessions have focused on the genetics of connective tissue and the review of new matrix proteins and functions, which should be informative on the subject and help provide additional directions for research. The importance of meetings of this sort, besides facilitating collaboration in the research community, will be the encouragement and interest of young fellows who will be introduced to the field of connective tissue and matrix biology.

In 2005, the Pan Pacific Connective Tissue Societies Symposium included a session on HDCT, which reviewed the over ten years of investigation in the basic cause of these complex multi-system genetic disorders. The meeting utilized a creative approach to the subject focusing on new findings and the multidisciplinary approach to the question of pathogenesis of connective tissue disease. Examples of the subjects on the program are: “Transcription Factors in Development of Connective Tissue;” “Matricellular Proteins;” “Growth Factors;” and the “Structure of Extracellular Matrix Molecules.”

RECOMMENDATION: We commend the Committee for its support of the National Institutes of Health and NIAMS continued acknowledgement of the need for HDCT symposia and workshop meetings. Your support of the 1990; 1995; and 2000 symposia held at NIH were key to the advances which have followed this collaborative effort. This multidisciplinary approach both within NIAMS, and between the Institutes, should continue in 2010 and 2011, and further incorporate symposia and research related meetings to foster communication and research advances to promote the cross-fertilization of research. The facilitating of NIH research sharing serves to avoid wasteful duplication and provides a springboard for the future direction of research in all areas relating to these HDCT diseases.

What is so important about the study of these disorders is their very complexity. The mutations of HDCT affect all body systems and require particular depth of investigation. This very complexity informs the researcher, as well as contributes to the understanding of other more common disorders. Research on these disorders in all of the body systems, will “spill” over into research into many of the categories identified in both the short range and the long range strategic plans for NIH and NIAMS, and provides benefits for many diseases beyond the scope of HDCT. Beyond this, the goal of alleviating pain and suffering, and saving lives, remains the most important imperative to the study of HDCT.

We thank you for this opportunity to thank the Committee for its past support and to voice the interests and concerns of the CHCDT member organizations relating to future priorities of NIH and the NIAMS.

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CORPORATION FOR MENKES DISEASE (CMD)
DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSO.OF AMERICA
(DebRA)
EHLERS-DANLOS NATIONAL FOUNDATION (EDNF)
LITTLE PEOPLE OF AMERICA (LPA)
LOEYS'DIETZ FOUNDATION (LDF)
NATIONAL ASSOCIATION FOR PSEUDOXANTHOMA ELASTICUM (NAPE)
NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS (NFED)
NATIONAL MARFAN FOUNDATION (NMF)
OSTEOGENESIS IMPERFECTA FOUNDATION (OIF)
PXE INTERNATIONAL, INC. (PXE)
SOCIETY FOR MITRAL VALVE PROLAPSE SYNDROME (SMVP)
STICKLER INVOLVED PEOPLE(SIP)
WILLIAMS SYNDROME ASSOCIATION (WSA)

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Statement of the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) on FY 2011 Funding for the National Institutes of Health submitted for the record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations, U.S. House of Representatives
The Honorable David Obey, Chair, April 16, 2010

Mr. Chairman and Members of the Subcommittee, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) appreciates and welcomes the opportunity to comment on the Fiscal Year (FY) 2011 appropriations for the National Institutes of Health (NIH). CAHT-BSSR includes 13 professional organizations, scientific societies, coalitions, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. Collectively, we represent more than 120 professional associations, scientific societies, universities, and research institutions.

CAHT-BSSR would like to thank the Subcommittee and the Congress for its continued support of the National Institutes of Health. Strong sustained funding is essential to national priorities of better health and economic revitalization. Providing adequate resources in FY 2011 that allows the NIH to keep up with the rising costs of biomedical, behavioral, and social sciences research will help NIH begin to prepare for the era beyond recovery. It is essential that funding in FY 2011 and beyond allow the agency to resume steady, sustainable growth and allow for fulfilling the President's vision of doubling our investment in basic research. **Accordingly, CAHT-BSSR joins the Ad Hoc Group for Medical Research in its request for \$35 billion in funding for NIH in FY 2011.** This level of funding will sustain America's enhanced medical research capacity. It also represents the new functional capacity funded by annual appropriations and the historic American Recovery and Reinvestment Act (ARRA).

NIH Behavioral and Social Sciences Research -- NIH supports behavioral and social science research throughout most of its 27 institutes and centers. The behavioral and social sciences regularly make important contributions to the well-being of this nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous contribution behavior makes to our health. At a time when genetic control over diseases is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the nation's battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance use and abuse, and mental illness.

As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

The grandest challenge we face is understanding the brain, behavior, and society -- from global warming to responding to short term pleasures; from self destructive behavior, such as addiction, to life style factors that determine the quality of life, infant mortality rate and longevity. Nearly 125

Coalition for the Advancement of Health Through Behavioral and Social Sciences Research

million Americans are living with one or more chronic conditions, like heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. Significant factors driving the increase in health care spending in the United States are the aging of the U.S. population, and the rapid rise in chronic diseases, many caused or exacerbated by behavioral factors: for example, obesity, caused by sedentary behavior and poor diet; addictions and resulting health problems caused by tobacco and other drug use. Behavioral and social sciences research supported by NIH is increasing our knowledge about the factors that underlie positive and harmful behaviors, and the context in which those behaviors occur.

CAHT-BSSR applauds the NIH's recognition that the "scientific challenges in developing an integrated science of behavior change are daunting." We especially commend the **new basic behavioral and social science research trans-NIH initiative, *Opportunity Network for Basic Behavioral and Social Sciences Research (OppNet)*, being undertaken by the NIH** to examine the important scientific opportunities that cut across the structure of NIH and designed to look for strategic opportunities to build areas of research where there are gaps and that have the potential to affect the missions of multiple institutes and centers. Research results could lead to new approaches for reducing risky behaviors and improving health.

Likewise, we commend the designation of the "**Science of Behavior Change**" Roadmap Initiative included in the third cohort of research areas for the Common Fund. We agree with the goals of this Roadmap Pilot to "establish the groundwork for a unified science of behavior change that capitalizes on both the emerging basic science and the progress already made in the design of behavioral interventions in specific disease areas. By focusing basic research on the initiation, personalization, and maintenance of behavior change, and by integrating work across disciplines, this Roadmap effort and subsequent trans-NIH activity could lead to an improved understanding of the underlying principles of behavior change. This should drive a transformative increase in the efficacy, effectiveness, and (cost) efficiency of many behavioral interventions."

With the recent passage of health care reform legislation, there has been the accompanying and appropriate attention to the issue of **personalized health care**. CAHT-BSSR believes that personalization needs to reflect genes, behaviors, and environments. And as the agency has acknowledged with its recent support of the Science of Behavior Change initiative, assessing behavior is critical to helping individuals see how they can improve their health. It is also critical to helping health care systems see where it needs to put resources for behavior change. Fortunately, the NIH acknowledges the need to focus less on finding the "magic answer" and, at the same time, recognizes that health care is different from region to region across the country. Full personalization needs to consider the environmental, community, and neighborhood circumstances that govern how individuals' genes and behavior will influence their health. For personalized health care to be realized, we need a sophisticated understanding of the interplay between genetics and the environment, broadly defined.

CAHT-BSSR applauds the NIH's recognition of a unique and compelling need to promote **diversity in health-related research**. The agency expects these efforts to lead to: the recruitment of the most talented researchers from all groups; an improvement in the quality of the educational and training environment; a balanced perspective in the determination of research priorities; an improved ability to recruit subjects from diverse backgrounds into clinical research; and an improved capacity to address

and eliminate health disparities. Numerous studies provide evidence that the biomedical and educational enterprise will directly benefit from broader inclusion.

NIH recognizes that developing a more diverse and academically prepared workforce of individuals in S.T.E.M. disciplines will benefit all aspects of scientific and medical research and care. CAHT-BSSR applauds the agency its recognition that to remain competitive in the 21st century global economy, the nation must foster new opportunities, approaches, and technologies in math and science education. This recognition extends to the need for a coordinated effort to bolster **science, technology, engineering, and math (S.T.E.M.)** education nationwide, starting at the earliest stages in education. We applaud the agency for its use of ARRA funds to support research designed to strengthen and enhance efforts to attract young people to biomedical and behavioral science careers and to improve science literacy in adults and children.

CAHT-BSSR also commends the NIH for commissioning the **Institute of Medicine (IOM) study of LGBT (lesbian, gay, bisexual, and transgender) health issues, research gaps and opportunities**. LGBT populations are among those for whom little or no national-level health data exist resulting in significant gaps in knowledge and research on LGBT health. At the same time, multidisciplinary research has begun to identify important sexual orientation and gender identity-related health concerns and disparities. The IOM study is a step in the right direction to begin to address many of the research challenges this issue presents, including methodological limitations. The study could examine the best methodological practices for investigating health concerns in LGBT communities. It also provides the opportunity for the development of a strategic plan for the NIH to investigate and address the health concerns of LGBT people. At the very least, the IOM study could examine the current state of knowledge on LGBT health, including general health concerns and health disparities.

NIH Office of Behavioral and Social Sciences Research

The NIH Office of Behavioral and Social Sciences Research (OBSSR), authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995, serves as a convening and coordinating role among the institutes and centers at NIH. In this capacity, OBSSR develops, coordinates, and facilitates social and behavioral science research agenda at NIH; advises the NIH director and directors of the 27 Institutes and Centers; informs NIH and the scientific and lay publics of social and behavioral science research findings and methods; and trains scientists in the social and behavioral sciences. **For FY 2011, CAHT-BSSR supports a budget of \$41.32 million for OBSSR commensurate with the Administration's request of \$38.2 million for the Office and the scientific community's request for the NIH as a whole.**

To achieve its vision of bringing together the biomedical, behavioral, and social sciences research communities to work towards solving the most pressing health challenges faced by society, OBSSR is expanding its efforts to promote and support social and behavioral science research in four areas: 1) problem-based research; 2) basic science; 3) systems-thinking approaches to population health; and 4) interdisciplinary team science. Given the NIH's focus on gene and environment interaction, new leading edge research examining how social and behavioral factors change or alter the actions of genes to influence health and disease is needed.

OBSSR focuses on cross-cutting behavioral and social research issues (e.g. “Long-term Maintenance of Behavior Change”) using its modest budget to seed cross-institute research initiatives. OBSSR has spurred cutting edge research in areas such as measures of community health, including new community-based participatory programs supporting intervention research methods to disease prevention and health promotion in medically underserved areas; socioeconomic status; health literacy; and new methodology development.

In FY 2011, OBSSR, in addition to continuing to support cross-cutting behavioral and social science research issues intends to address the issue of **health literacy**. Low health literacy is a wide spread problem, affecting more than 90 million adults in the United States, where 43 percent of adults demonstrate only the most basic or below-basic levels of prose literacy. Low health literacy results in patients’ inadequate engagement in decisions regarding their health care and can hinder their ability to realize the benefits of health care advances. Research has linked low or limited health literacy with such adverse outcomes as poorer self-management of chronic diseases, fewer healthy behaviors, higher rates of hospitalizations, and overall poorer health outcomes. These situations hamper the effectiveness of health professionals’ efforts to prevent, diagnose and treat medical conditions, and limit many health care consumers’ abilities to make important health care decisions.

The following research cited in the *Achievements of the Social And Behavioral Sciences: Improving Health at Home and Abroad* compiled by the OBSSR further illustrates why behavioral and social sciences research is a critical component in generating scientific knowledge to prevent, treat or cure illnesses or enhance health in a broader context.

Understanding the Links Between Social and Cultural Factors and Health: Social scientists have made significant strides in shedding light on the basic social and cultural structures and processes that influence health. Social and cultural factors influence health by affecting exposure and vulnerability to disease, risk-taking behaviors, the effectiveness of health promotion efforts, and access to, availability of, and quality of health care. Social and cultural factors also play a role in shaping perceptions of and responses to health problems and the impact of poor health on individuals’ lives and well-being. In addition, such factors contribute to understanding societal and population processes such as current and changing rates of morbidity, survival, and mortality.

Transforming Health and Health Care - Even with the dramatic contributions that behavioral and social sciences research has made to date, much more needs to be done to understand the role of behavioral and social factors in disease and to use that knowledge to improve the Nation’s health. There is strong evidence that half of all deaths in the U.S. can be attributed to behavioral factors such as smoking, poor diet, and physical inactivity. In addition, behavioral and social factors contribute to the staggering costs of preventable morbidity and mortality. Undoubtedly, biomedical discoveries like the mapping of the human genome have transformed medicine over the past 20 years. Breakthroughs in the behavioral and social sciences over the next 20 years will be critical to address our most pressing public health challenges and to transform health care.

Gene by Environment Interactions - The longstanding debate about nature versus nurture has been turned on its head. Scientists now recognize that it is not a question of genes or environment, but rather, how genes and environment interact in complex ways to explain virtually every observable trait. Take the link between stress and depression: recent research has demonstrated that genetic

vulnerability plays a key role in explaining why stressful life events result in depressive symptoms, diagnosable major depression, and suicide attempts among some individuals but not others. In the same way that “personalized medicine” may tailor medical treatment based on an individual’s genetic makeup, behavioral and social science interventions will also benefit from a more sophisticated understanding of the interactions among genetic, personal, and environmental factors in human behavior.

Improving Mental Health - Over the past 30 years, our understanding of the bio-behavioral mechanisms and treatment of mental disorders has advanced dramatically. Effective and cost-effective therapies that combine behavioral and pharmacological treatments are now available for treatment of depression, anxiety disorders, and the abuse of nicotine, alcohol and other drugs.

Reducing the Health Burden of Poverty - Discoveries in the behavioral and social sciences can inform life-saving environmental and policy changes. One example is the PROGRESA study (Programa Nacional de Educacion, Salud, y Alimentacion), an anti-poverty program begun in 1997 that provides aid to 2.6 million poor Mexican families. This study is comprised of an impressive collaboration across disciplines including biomedical, social/behavioral sciences, economics, epidemiology, and demography. The results have been dramatic, showing that the trajectory of health outcomes associated with poverty may be altered within a generation. The PROGRESA intervention was associated with better growth and lower rates of anemia in low-income, rural infants and children in Mexico. This large-scale, real-world study has demonstrated that antipoverty programs that combine education, health, and nutrition interventions can improve the capacity of families to pull themselves out of poverty and adverse health effects that often ensnare generations.

Preventing Diabetes - For many years, scientists believed that medication was the only tool to prevent and treat diabetes. The Diabetes Prevention Program demonstrated that lifestyle interventions – modest weight loss and regular physical activity – can reduce the risk of developing type 2 diabetes in high-risk adults by 58 percent, compared to 31 percent reduction with diabetes medication. These findings led to “Small Steps, Big Rewards”, the first national diabetes prevention campaign.

Increasing Life Expectancy and Quality of Life - In the last century, life expectancy has extended by an astounding amount—from 47 years in 1900 to 77.5 years in 2003. While medical advances increasingly contribute to living longer and healthier lives, the vast majority of improvements in the quality of life have come from changes in our social, economic, and physical environments.

CAHT-BSSR would be pleased to provide any additional information on these issues. Below is a list of coalition member societies. Again, we thank the Subcommittee for its generous support of the National Institutes of Health and for the opportunity to present our views.

CAHT-BSSR

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|--|--|
| American Educational Research Association | Federation of Associations in Behavioral & Brain Sciences |
| American Psychological Association | National Association of Social Workers |
| American Sociological Association | Population Association of America |
| Association of Population Centers | Society for Behavioral Medicine |
| Center for the Advancement of Health | Society for Research in Child Development |
| Consortium of Social Science Associations | The Alan Guttmacher Institute (AGI) |
| Council on Social Work Education | |

Coalition for the Advancement of Health Through Behavioral and Social Sciences Research

**Statement of the Coalition of Northeastern Governors
to the
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies
Committee on Appropriations
U.S. House of Representatives
Regarding FY2011 Appropriations for
the Low Income Home Energy Assistance Program
April 13, 2010**

The Coalition of Northeastern Governors (CONEG) is pleased to submit this testimony for the record to the House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies regarding FY2011 appropriations for the Low-Income Home Energy Assistance Program (LIHEAP).

The Governors appreciate the Subcommittee's continued support for LIHEAP, and we thank you for providing \$5.1 billion in FY2010 funding for the program. The Governors recognize the considerable fiscal challenges facing the Subcommittee this year. However, as the number of households seeking heating and cooling assistance continues to increase nationwide, we urge you to provide FY2011 funding for the core LIHEAP block grant program at least at the most recent authorized level of \$5.1 billion, as well as provide sufficient contingency funds to address unforeseen energy emergencies. Providing this funding level through the block grant program provides the certainty that states need to implement an effective program.

LIHEAP is a vital safety net for millions of vulnerable low-income households – the elderly and disabled living on fixed incomes, the working poor and newly unemployed, and families with young children. Under this targeted program, the majority of households receiving assistance have incomes of less than \$8,000 a year. These households have the highest energy burden, spending more than 16 percent of their income on home energy compared to 3 percent for non-low-income households.

This disproportionate energy burden experienced by vulnerable low-income families continues. In recent years, the increase in the cost of home energy has far outpaced both the rate of inflation and the increase in household income.¹ The share of income that elderly households spend on housing costs and out-of-pocket health care expenditures has increased substantially in the last two decades.² LIHEAP is an effective tool for helping these households better manage the financial pressures of unaffordable home energy costs, through assistance in paying bills as well as making their homes and heating systems safer and more efficient.

¹ *Short and Long-Term Perspectives: The Impact on Low-Income Consumers of Forecasted Energy Price Increases in 2008 and a Cap-and-Trade Carbon Policy in 2030*, Oak Ridge National Laboratory, December 2007.

² *Reciprocity Targeting Analysis for Elderly and Young Child Households*, prepared for the Office of Community Services' Division of Energy Assistance by APPRISE Incorporated, December 2008.

While some national economic reports are hopeful, the current situation remains challenging for these low-income households as the costs of essential household expenses including home energy and food remain high. This is particularly true in the Northeast where a greater percentage of households use delivered heating fuels, such as home heating oil, propane and kerosene, than in any other region of the country. These households are more vulnerable to price volatility, making it more difficult for families to manage their household budgets. Households using deliverable fuels tend to have an extremely high energy burden, with historically higher energy bills than those using other heating sources. The average annual heating bill for all LIHEAP recipients was \$717 in 2007. However, the average annual heating bill for households using home heating oil was \$1,686, and the average heating bill for propane users was \$1,052.³ This pattern continues. Even as the price of some home energy prices stabilize, the Energy Information Administration finds that home heating oil prices have increased 20 percent over last year.⁴ In addition, households that rely upon delivered fuels do not have the benefit of a program comparable to a utility service shut-off moratorium. If a household cannot afford to purchase the home heating fuel, the delivery truck simply does not come.

The number of households receiving LIHEAP assistance continues to reach record levels. According to the National Energy Assistance Directors' Association (NEADA), 8.3 million households received heating assistance in 2009, compared to 6.1 million in 2008. States expect that number to grow to more than 9.5 million in 2010. Many of these applicants have never requested help before, but are facing extraordinary economic hardship due to increased unemployment and layoffs. Yet, this is only a small portion of the eligible households.

As spring approaches and utility shut-off moratoria end, too many families are in danger of having their utility service terminated for non-payment. According to NEADA, approximately 4.3 million households were shut off from power in FY2009 up from 4.1 million in 2008. In FY2009 approximately 12.5 million households were at least 30 days behind in their utility bills. The effects on these vulnerable households can be deadly. Numerous studies have found that the elderly and very young children are at risk for serious health consequences from prolonged exposure to home temperatures that are either too cold in the winter or too hot in the summer.

States in the Northeast already incorporate various administrative strategies that allow them to deliver maximum program dollars to households in need. These include using uniform application forms to determine program eligibility, establishing a one-stop shopping approach for the delivery of LIHEAP and related programs, sharing administrative costs with other programs, and using mail recertification. Opportunities to further reduce LIHEAP administrative costs are limited, since they are already among the lowest of the human service programs.

³ *LIHEAP Home Energy Notebook for Fiscal Year 2007*, U.S. Department of Health and Human Services, Administration for Children and Families, Office of Community Services, Division of Energy Assistance, June 2009.

⁴ *Short-Term Energy Outlook*, Energy Information Administration, March 2010.

In spite of these state efforts to stretch federal and state LIHEAP dollars, the need for the program is far too great. Increased, predictable and timely federal funding is vital for LIHEAP to assist the nation's vulnerable, low-income households faced with exorbitant home energy bills. The CONEG Governors urge the Subcommittee to provide at least \$5.1 billion in regular block grant funding for LIHEAP in FY2011 as well as sufficient contingency funds to address unforeseen energy emergencies. This sustained level of funding will help states to provide meaningful assistance to households in need as millions of low-income citizen's struggle with unaffordable home energy bills. LIHEAP can continue to provide a vital safety net protecting these vulnerable households from the potentially deadly heat and cold.

Submitted on behalf of CAEAR Coalition:

**Ernest Hopkins, Chair
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On behalf of the tens of thousands of individuals living with HIV/AIDS to whom the members of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition provide care, I want to thank Chairman David Obey and Ranking Member Todd Tiahrt for affording CAEAR Coalition the opportunity to submit this written testimony for the record regarding increased funding for the Ryan White HIV/AIDS Program.

CAEAR Coalition is a national membership organization which advocates for federal appropriations, legislation, policy and regulations to meet the care, treatment, support service and prevention needs of people living with HIV/AIDS and the organizations that serve them. CAEAR Coalition's proactive national leadership is focused on the Ryan White Program as a central part of the nation's response to HIV/AIDS. CAEAR Coalition's members include Ryan White Program Part A, Part B, and Part C consumers, grantees, and providers.

A Wise Investment in a Program That Works

The Ryan White Program works. Those on the epidemic's frontlines know this to be true, and that faith received a ringing endorsement from the White House Office of Management and Budget (OMB). In its 2007 Program Assessment Rating Tool (PART), OMB gave the Ryan White Program its highest possible rating of "effective"—a distinction shared by only 18% of all programs rated. According to OMB, effective programs "set ambitious goals, achieve results, are well-managed and improve efficiency." Even more impressively, OMB's assessment of the Ryan White Program found it to be in the top 1% of all federal programs in the area of "Program Results and Accountability." **Out of the 1,016 federal programs rated—98 percent of all federal programs—the Ryan White Program was one of seven that received a score of 100% in "Program Results and Accountability."**

The reauthorization of the Ryan White Program signed in October 2009 was a tremendous victory for people living with HIV/AIDS and those who care for them. We are grateful for Congressional efforts to ensure that this vital program continued uninterrupted when it expired in September. As you are aware, the Ryan White Program serves as the indispensable safety net for thousands of low-income, uninsured or underinsured people living with HIV/AIDS.

- Part A provides much-needed funding to the 56 major metropolitan areas hardest hit by the HIV/AIDS epidemic with severe needs for additional resources to serve those living in their communities.
- Part B assists states and territories in improving the quality, availability, and organization

- of health care and support services for individuals and families with HIV disease.
- The AIDS Drug Assistance Program (ADAP) in Part B provides urgently needed medications to people living with HIV/AIDS in all 50 states and the territories.
- Part C provides grants to 357 faith and community based primary care health clinics and public health providers in 49 states, Puerto Rico and the District of Columbia. These clinics play a central role in the delivery of HIV-related medical services to underserved communities, people of color, and rural areas.
- Part F AETC supports training for health care providers to identify, counsel, diagnose, treat, and manage individuals with HIV infection and to help prevent high-risk behaviors that lead to infection. It has 130 program sites in all 50 states.

We thank you in advance for your consideration of our comments and our request for:

- \$905 million for Part A to support grants to the cities hardest hit by HIV/AIDS so they can provide quality care to people with HIV/AIDS (an increase of \$225.9 million);
- \$474.7 million for Part B base to provide additional needed resources to the states in their efforts to address the HIV/AIDS epidemic (an increase of \$55.9 million).
- \$1205.1 million in funding for the ADAP line item in Part B so uninsured and underinsured people with HIV/AIDS can access the prescribed medications they need to survive (an increase of \$307.1 million)
- \$337.8 million for Part C to support grants to community-based organizations, agencies, and clinics that provide quality care to people living with HIV/AIDS (an increase of \$131 million).
- \$50 million to fund the 11 regional centers funded under by Part F AETC to offer specialized clinical education and consultation on HIV/AIDS transmission, treatment and prevention to frontline healthcare providers (an increase of \$15.9 million).

The increases CAEAR Coalition seeks in the current funding for Part A, Part B base and ADAP, Part C, and Part F AETC reflect the reality that the HIV/AIDS epidemic and the health care and social service needs of people with HIV/AIDS require significantly more federal resources than those provided in recent years. There continues to be an ever-growing gap between the number of people living with AIDS in the U.S. in need of care and the resources available to serve them. For example, between 2001 and 2007 the number of people living with AIDS grew 33% and yet funding for medical care and support services in the nation's hardest hit communities grew less than 12% between 2001 and 2010. Similarly, funding for Part C-funded, community-based primary care clinics, which provided medical care for people living with HIV/AIDS in rural and urban communities nationwide, grew by only 11% between 2001 and 2010 as the number of people they care for grew by 52%.

Growing Needs, Diminishing Resources

In 2008, CDC yet again revised upward its estimate of persons living with HIV/AIDS in the U.S. to 1,106,400 (as of 2006). Approximately one-half of those people have yet to access HIV-related medical care and there is a projected influx of newly diagnosed individuals into care as a result of CDC initiatives to promote routine HIV testing. CDC also estimates that in 2006, over 56,000 people were newly infected with HIV. Ryan White Program Part A, Part B base and ADAP, Part C, and Part F AETCs must receive adequate increases to meet the health care and supportive

services needs of individuals already in care and those newly identified HIV patients entering care—many of whom will require comprehensive medical treatment and supportive services at the time of diagnosis.

Additional increases are desperately needed to address the growing demand for services, offset the rising cost of care, and help the many jurisdictions forced year after year to make service reductions and eliminations to rebuild their programs.

State budget cuts have created an immediate ADAP funding crisis. Many state ADAPs are on the brink of the worst funding shortfall in many years and there is a record number of people in need of ADAP services due to the economic downturn. As of March 2010, there are 662 people on ADAP waiting lists in 10 states. Additionally, ADAP waiting lists and other cost-containment measures, including limited formularies, reducing eligibility, or removing already enrolled people from the program, are clear evidence that the need for HIV-related medications continues to outstrip availability. ADAPs are forced to make difficult trade-offs between serving a greater number of people living with HIV/AIDS with fewer services or serving fewer people with more services. Additional resources are needed to reduce and prevent further use of cost-containment measures to limit access to ADAPs and to allow all state ADAPs to provide a full range of HIV antiretrovirals and treatment for opportunistic infections.

The number of clients entering the 357 Part C community health centers and outpatient clinics has consistently increased over the last five years. Over 248,000 persons living with HIV and AIDS receive medical care in Part C–funded community health centers and clinics each year. These community- and faith-based HIV/AIDS providers are staggering under the burden of treatment and care after years of funding cuts prior to the modest increase in recent years. The CDC has implemented a number of initiatives designed to promote routine HIV testing to identify people living with HIV. Their success continues to generate new clients seeking care at Part C–funded health centers and clinics with no commensurate increase in the funds necessary to provide access to comprehensive, compassionate treatment and care.

Increasing Testing Requires Increasing Access to Care

The FY 2011 appropriation presents a crucial initial opportunity to restore the Ryan White Program to the levels of funding demanded by the epidemic as the Centers for Disease Control and Prevention continue their increased efforts to expand HIV testing to help people living with HIV learn their status. With the continued influx of newly diagnosed individuals into care and the additional 56,000 estimated new cases of HIV every year, the Ryan White program must receive adequate increases to meet the health care and supportive services needs of individuals already in care and those newly identified HIV patients.

CAEAR Coalition supports efforts to help identify those individuals infected with HIV but unaware of their status. However, CAEAR Coalition is concerned that without the simultaneous allocation of additional resources for treatment, these CDC initiatives have resulted in a significant increase in the demand for HIV/AIDS services without the capacity in place to provide that care.

Increased demand for services has placed a severe strain on the HIV/AIDS safety net and forced community-based providers to stretch already scarce resources even further to address growing needs. This additional pressure on an already overburdened system will leave many of the 200,000+ HIV-infected individuals who do not know their HIV status without access to the care they need. CAEAR Coalition urges Congress and the Administration to provide a commensurate increase for treatment programs to meet the demand that has resulted from the CDC testing initiative.

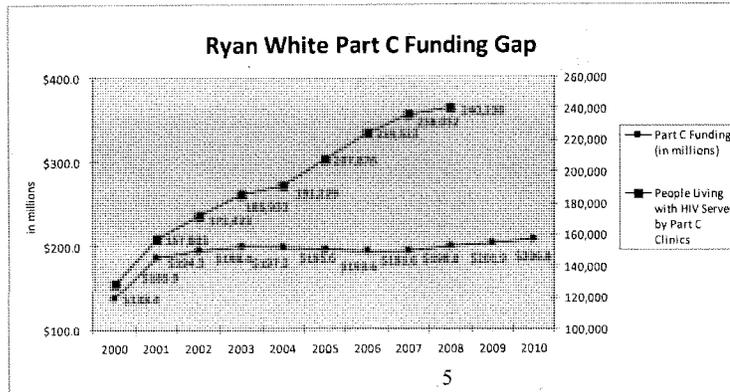
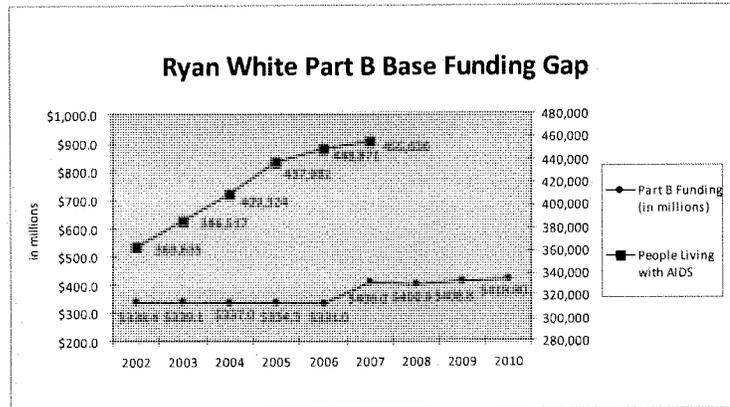
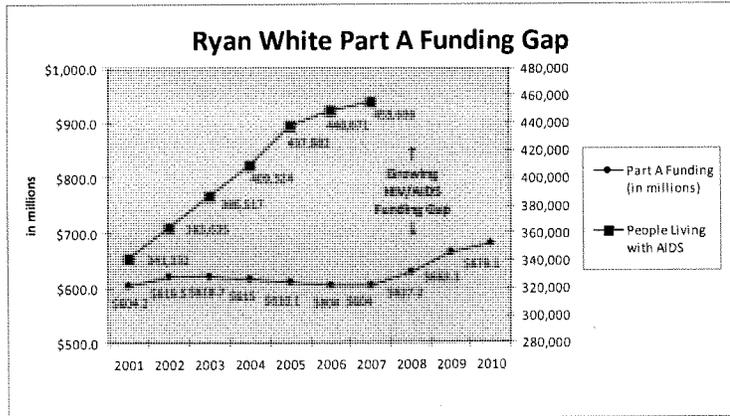
Sufficient Funding for Ryan White Programs Saves Money and Saves Lives

Increased funding for Ryan White Programs will reap a significant health return for minimal investment. Data show that Part A and Part C programs have reduced HIV-related hospital admissions by 30 percent nationally and by up to 75 percent in some locations. The programs supported by the Ryan White HIV/AIDS Program also have been critical in reducing AIDS mortality by 70 percent. Taken together, the Ryan White Program works – resulting in both economic and social savings by helping keep people healthy and productive.

CAEAR Coalition is eager to work with Congress to meet the challenges posed by the HIV/AIDS epidemic. Congress and the Administration must do more to address the grim reality that the domestic epidemic is not static; it is continuing to grow at a significant rate and more federal resources are needed to prevent it from becoming a public health catastrophe similar to what we are witnessing in the developing world. Already, some communities in the United States have infection and death rates similar to those in Africa. We must make a commensurate domestic investment to care for people in our own communities. CAEAR Coalition looks forward to working with the Committee and the Congress to help meet the needs of Americans living with HIV/AIDS as the appropriations process moves forward.

Given the Ryan White Program's stellar history of accomplishments, the vast need for more resources to address unmet need, and such strong praise from the federal government's most stringent and assiduous assessors, we hope the committee will act to provide these relatively modest funding increases.

Growing HIV/AIDS Funding Gaps, 2001-2010



↑ Growing HIV/AIDS Funding Gap ↓

↑ Growing HIV/AIDS Funding Gap ↓

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Dear Members of the House Appropriations Committee:

I would like to take this opportunity to speak up against the idea of a fee-based Voluntary Protection Programs (VPP). As an employee at a VPP site, I believe that this will be detrimental to the integrity of the program and the culture of proactive safety and health beyond compliance that it currently instills.

In his report to the House Budget Committee on March 4, 2010, Congressman George Miller (D-CA), chair of the House Committee on Education and Labor, supported the Department of Labor's (DOL) shift of funding and resources away from VPP in favor of enforcement. He proposed to fund VPP "through a user fee, and plans to work on establishing authority for augmenting the OSHA budget through a fee based system". Funding VPP through a user-fee system for certification would take away from the independent verification of our safety and health management system because it would lead to a direct relationship between number of VPP sites and fees paid to the government. Some repeated concerns expressed by many of our 921,000 American workers now covered by VPP include:

- * Industry directly funding the government to perform part of its required function under the OSH Act.
- * Creating the perception that employers are "buying" the VPP flag.
- * Creating a situation where employers can be perceived as purchasing "an exemption from routine OSHA inspections."
- * Fees for VPP deterring small businesses from participating.
- * Charging sites for participation in VPP despite of what VPP sites voluntarily give in the form of mentoring, outreach, assist visits, funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national conferences.
- * Paying a fee reduces VPP to a government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride.

In a way, America's worksites would be directly funding the Occupational Safety and Health Administration (OSHA) to perform its functions as required by the OSH Act and private industry and special interests' funding the Federal Government is against the law. The Occupational Safety and Health Act of 1970 requires 13 objectives to be accomplished. Only one of the 13 objectives is enforcement, two are standard setting, and three are directly related to the development of cooperation between employer and employee to establish a safe workplace - exactly what the founders of OSHA VPP established the program to accomplish. Congress

and DOL taking actions to shift funding from VPP in favor of enforcement is not a return to OSHA's 'roots in enforcement,' only an Agency ignoring 12 other mandates from Congress and asking American's worksites to provide that funding through a user fee-based system to pay the agency to implement all the requirements under the OSH Act.

Unlike many fee-based certification programs, VPP is a comprehensive workplace safety and health management system that is built on cooperation among workers, employers and government. If the DOL backs away from the partnership, it diminishes the program instead of strengthening OSHA's partnership with corporate America in an effort to push beyond outdated standards.

While I continue to support firm and fair enforcement as a necessary tool to reach worksites that are not voluntarily improving their safety and health programs, I firmly believe that there is clear evidence that 40 years of enforcement has failed in producing the necessary culture shift that is required to achieve measurable and sustainable improvements in the protection of the American workforce and to keep American businesses competitive in a global marketplace.

It is clear that 40 years of enforcement have left American's small businesses - collectively the largest employers and source of future "good jobs" - lacking. Under any administration, OSHA's dealings with America's small businesses has either been 'hands-off' or "penalize to closure," because those are the only two options in an Agency focusing solely on enforcement. In recent years, smaller worksites have increased significantly within VPP, growing from 28 percent of VPP sites in 2003 to 39 percent in 2008, thanks to innovations such as mentoring and the VPP Challenge Program. These innovations are keeping employees safer at worksites that traditionally would not see an OSHA compliance inspection or, if fined, might have to go out of business or at the very least provide lay-off notices to employees to cover the citation and associated penalties. These worksites have seen the value in a proactive safety program, such as VPP, that is saving companies and taxpayers money.

In 2007, OSHA evaluated the benefits of the VPP and reported that Federal Agency VPP participants, in OSHA, the Department of Energy (DOE), the Department of Defense (DOD), and the National Parks Service, to name a few, saved the government more than \$59 million by avoiding injuries and the private sector VPP participants saved more than \$300 million. These funds are a return on investment that are funneled into new equipment, expanding production, creating 'good jobs,' keeping 'good jobs,' and voluntarily mentoring other work sites in the community to learn the value of VPP and keeping American workers safe. That money should not be used to fund the Federal Government to perform its required obligations under the OSH Act.

The Federal Government already benefits from its involvement in VPP and from the private sector's participation in VPP, such as:

* The \$59 million saved by Federal Agency participants in VPP is money that demonstrates fiscal responsibility and cost avoidance and allows for the reallocation of resources to the mission of the Agency.

* The U.S. Department of Labor's Safety, Health, and Return-to-Employment (SHARE) initiative was launched in 2004 to help the Federal Government in

reducing injury and illness cases and lost production day rates, and to substantially improve timely filing of injury and illness notices. Agencies that adopted VPP achieved greater and sustainable improved performance in the SHARE initiative and want to expand the VPP throughout their operations.

* The DOD, with 31 VPP sites, has seen a substantial return on investment by adopting VPP in terms of reduced injuries and illnesses and a strong improvement in maintaining mission-readiness.

* In 2003, the DOE Appropriations language noted a dramatic improvement in the safety and health within the Complex and challenged DOE to "maintain worker safety and health performance at least to levels seen in 2002," that performance was achieved by 21 VPP sites in the DOE Complex.

* The cost avoidance in workers compensation for a single contractor in the DOE Complex was a \$3 million cost reduction in three years by working toward and installing VPP. That was \$3 million in taxpayers' money redirected to the DOE mission, just by preventing worker injuries.

* OSHA also directly benefits by reducing employee injuries and illnesses at three of its Regional Field Offices that are VPP.

* Additionally, when workplaces make the significant commitment to safety required by VPP, it allows OSHA to focus its resources of enforcement where they are most needed - on those companies that "don't get it" - as stated by the Secretary of Labor.

Recent tragic events in the American workplace cause us great concern, such as the mining disaster in West Virginia and the refinery explosion in Washington state. These events remind us that when we continue to return to only one tool in OSHA's toolbox to achieve a safe workplace - and that tool is enforcement - that we will never achieve, as a nation, the necessary culture, mindset and attributes necessary to protect our most valued asset - the American worker. Each of these tragic examples, worksites and employers had received routine inspections and citations from OSHA and the Mine Safety & Health Administration (MSHA) compliance officers. Those visits were routine, on average five inspections in the past seven years, all with citations and large fines. These events demonstrate what 40 years of enforcement have achieved; and why would recapitulating this lesson return different results? Would more workers go home to their families at night?

Instead, what if on just one of those OSHA or MSHA inspections the compliance officer would have recommended the company enter into the VPP Challenge Program?

- What if, through OSHA's VPP, one of those companies had learned the value, in human preservation and financially, of preventing accidents and avoiding costs and impacts to the bottom line?

- What if one of those companies was the first in their industry to demonstrate that safety and profitability are achievable together?

- What if others in their industry took notice and started to embrace the same ideas and sought to achieve VPP status in order to maintain a competitive edge?

Would more workers then go home to their families at night?

I ask you to speak out against the idea of a fee-based Voluntary Protection Programs and to ensure the continued success of OSHA's VPP as a cooperative

program by reinstating direct and continued funding in the DOL budget. Highly successful cooperative programs like VPP should be funded and expanded if OSHA is to assist American businesses in achieving the necessary cultural change required to maintain and protect American workers, which is a proven method that supports OSHA's mission. I ask that you provide full funding in the DOL budget for VPP and include specific Appropriations language to restore and direct the Agency to fund, resource load and conduct VPP assistance, application evaluations, onsite re-approvals and new onsite evaluations to the levels equal to or greater than those achieved in 2005.

Sincerely,

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**Statement of Patricia Harrison
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 (202) 879-9662 or pharrison@cpb.org
 Before the Subcommittee on Labor, Health and Human Services, Education and
 Related Agencies, U.S. House Committee on Appropriations
 April 16, 2010**

Chairman Obey, Ranking Member Tiahrt, and members of the subcommittee, thank you for allowing me to submit testimony on behalf of our nation's public media system.

As you know, the Corporation for Public Broadcasting (CPB), a private, nonprofit corporation created by the Public Broadcasting Act of 1967, is the steward of the federal government's investment in public broadcasting. We support the operations of more than 1,100 locally-owned and -operated public television and radio stations nationwide. Throughout the U.S., public broadcasting, or what should more accurately be called "public media," engages citizens on-air, on-line, and on the ground with information they can use to improve their lives and strengthen their local communities. As commercial media becomes increasingly consolidated, a key strength of public media remains its design: a decentralized set of stations, each with deep local roots and maintaining individual service strategies tailored to the unique needs of its local community.

Public broadcasting was born in an earlier moment of profound change and transition. In the 1950s and 1960s a new media technology was diffusing quickly: the television. Around it grew a movement to use the new medium, as well as existing radio technology, for educational purposes, and public broadcasting was born. Today, nearly a half-century after the signing of the Public Broadcasting Act, we are making a similar transition from public broadcasting to the "Public Media 2.0" the President called for during his campaign. As we leverage our legacy to become a leader in the new and ever-changing media landscape, public media has focused its efforts through a strategic framework comprising the "Three Ds": Digital, Diversity and Dialogue.

Innovation on DIGITAL Platforms

As an outgrowth of its dedication to universal service, public media is embracing a range of digital delivery methods to reach all Americans, wherever and whenever they seek information. Because of its reach, its availability for free, and its unmatched efficiency in point-to-multipoint communications, over-the-air service remains an essential part of the public media portfolio. At the same time, public broadcasters are evolving into true multi-platform media entities by creating content and services, some related to and some entirely independent from broadcast content, that capitalize on the power of broadband and other digital technologies. For example:

- KQED's (San Francisco) **QUEST** is a new multimedia series about the people behind Bay Area science and environmental issues which utilizes all of KQED's media platforms, educational resources and extraordinary partnerships, and includes a half-

hour weekly HD television program, weekly radio segments, an innovative website and education guides.

- Public Broadcasting Atlanta is developing *Lens on Atlanta*, an on-line portal that invites citizens to create and participate in blogs, wikis, forums, petitions, and surveys, and engages institutions and government entities around Atlanta to listen and participate.
- Many public radio stations have expanded the reach of their cultural programming by investing in and creating substantial internet music services with significant audiences. Examples include WAMU's *Bluegrass Country*, WKSU's *Folk Alley*, WXPB's *Xponential*, and KCRW's *Eclectic24*.

In addition to these local station efforts, public broadcasting's national organizations have been moving for some time to leverage the power of digital media. For example:

- CPB is funding the creation of **Local Journalism Centers**, combining our and participating stations' resources for a ground-breaking approach to newsgathering and distribution. The seven centers will form teams of multimedia journalists, who will focus on issues of particular relevance to each region, and their in-depth reports will be presented regionally and nationally via digital platforms, community engagement programs and broadcasts.
- In October 2009, NPR initiated **Argo**, a new multi-media journalism project, funded by CPB and the Knight Foundation. The two-year project is designed to strengthen public media's local journalism, build a significant online audience, and develop a common publishing platform that will better support public media's online needs. NPR is working with a dozen selected public television and radio stations to launch websites for each station that go in-depth on selected topics or "verticals."
- In September 2008, PBS launched its PBS KIDS GO! video player, featuring hundreds of video clips and dozens of full-length episodes. Since launch, the site is averaging 1.3 million streams per week, and nine million unique visitors a month. In December 2009 alone, children watched more than 87.5 million streams across the PBS KIDS family of Web sites, its highest total ever, putting it on track to be one of the most popular video sites in the world.
- CPB is funding the development of the **American Archive**, which ultimately will restore, digitize, and preserve public broadcasting's deteriorating collections of local television and radio content. We expect to have 40,000 hours of local and national television and radio content available to the American public with in 18 months.

Content that Reflects the Nation's DIVERSITY

Equally central to public media's universal service mission is providing individuals of

every ethnicity and economic and social background, particularly those that are underserved by commercial media, relevant and engaging content. The ability to transmit multiple streams of digital programming over the air, combined with the nearly boundless capabilities of broadband, enable local and national public media entities to deliver content that truly reflects America's diversity. CPB is constantly expanding its relationships with diversity partners to both broaden its reach and to allow greater opportunities, on a variety of platforms, for underrepresented groups. Among these efforts:

- CPB provides ongoing support to, among others: the **National Minority Consortia**, which provides seed money to producers of multicultural content; the **Independent Television Service**, which champions independently produced programming targeting underserved audiences; **Koahnic Broadcast Corporation**, the leader in bringing Native voices to Alaska and the nation through the only urban Native public radio station and its national production and distribution center (Native Voice One) in Albuquerque; and **Radio Bilingue**, the only national distributor of Spanish-language public radio programming, which is now developing a transmedia service in Los Angeles targeting a young, English-speaking, and highly diverse audience. We also funded the creation of **Native Public Media** in 2004 to build and advance Native access to, ownership of, and participation in media, especially radio.
- In FY 2010, we are creating within our multi-year PBS National Program Service agreement (which supports primetime and children's programming) a **Diversity and Innovation Fund**, which will support major content development projects that examine topics of interest to diverse audiences or that employ new, lower cost production models.
- CPB funds the National Black Programming Consortium's annual **New Media Institute**, a unique professional development program designed to introduce producers to the latest in digital media production, marketing and distribution. The program includes a collaboration website where journalists can showcase their work, find and share public domain stock, share best practices, and brainstorm together on innovative future citizen media projects.
- Through projects such as the Public Radio Talent Quest, CPB has identified a new generation of public broadcasting talent – **Public Media 2.0** producers – who appeal to new audiences and produce multimedia content for a variety of platforms. For example, Glynn Washington, a winner of the Talent Quest, produces a new multimedia series, *Snap Judgment*, that combines his unique brand of storytelling with innovative technology to explore the decisions people make in moments of crisis.

Services that Foster DIALOGUE Between Public Media and the American People

Public media's localism remains more relevant than ever as commercial media are

increasingly owned and operated by entities outside of their local communities – but the nature of our service to local communities is shifting in the digital age. Critical to public media’s future will be its ability to collaborate and serve as an active resource and trusted partner to more diverse communities, in new ways. Public media entities are quickly adapting to the new paradigm. For example, as part of a comprehensive local/national response to the nation’s economic woes, CPB is supporting a number of in-depth community engagement projects, including:

- **Facing the Mortgage Crisis:** 57 stations are participating in this multi-million dollar national project designed to help the country’s hardest-hit regions cope with an avalanche of mortgage foreclosures. Based on an extremely successful model developed by KETC-TV in St. Louis, stations are working with key community partners, such as United Way’s 2-1-1 call centers, to create content on-air and online that helps families to avoid or mitigate home foreclosures.
- **Engaging Communities on the Economy:** CPB is supporting the work of 37 stations working with partners to address other pressing economic issues, such as joblessness, hunger, loss of health insurance and family stress. These projects serve diverse audiences, from seniors to recent immigrants to teenagers.

CPB’s Requests for Appropriations:

Public media stations continue to evolve, both operationally and more importantly in the myriad ways they serve their communities. Stations are committed to reaching viewers and listeners on whatever platform they use – from smart phones to iPads to radios to TV sets. But new opportunities come with a cost. While stations can and will continue to adapt and thrive in the digital age, without sufficient support they cannot live up to the potential of the new technologies. As the Federal Communications Commission’s recently-issued National Broadband Plan noted, “Today, public media is at a crossroads...[it] must continue expanding beyond its original broadcast-based mission to form the core of a broader new public media network that better serves the new multi-platform information needs of America. To achieve these important expansions, public media will require additional funding.”

CPB Base Appropriation (FY 2013): CPB requests a \$604 million advance appropriation for FY 2013. Stations have been faced with flat CPB funding for the better part of the past decade, and the impact of this lack of an even inflationary increase (until FY 2010) has been magnified by the economic conditions of the last few years. As public media seeks to make the transition to a truly digital enterprise, the federal share of station funding has never been more critical. CPB distributes its advance appropriation in accordance with a statutory formula, under which almost 72 percent of funds go directly to local public television and radio stations, as well as discretionary support for the creation of programming for radio, television and new media and on projects that benefit the entire public broadcasting community. Added together, these efforts account for 95 percent of the funds appropriated to CPB; we are limited by law to an administrative

budget of five percent. The federal appropriation accounts for under 15 percent of the entire cost of public broadcasting, but it is a vital core that leverages support from state and local governments, universities, businesses, foundations, and especially viewers and listeners of local public television and radio stations.

CPB Digital (FY 2011): CPB requests \$59.5 million in digital funding for FY 2011. With this funding, CPB will continue its mission to fund stations' efforts to adapt to audience demands for educational, cultural and news and information content, regardless of platform. As the Administration noted in its FY 2011 budget request, while CPB Digital will continue to fund station "equipment" such as digital transmitters and translators, "the majority of this funding will be utilized to fund projects to enhance multi-platform content creation, delivery and storage, such as the American Archive, which by converting content to digital format, will ensure that the vast archives of public broadcasting content will not be lost due to physical media deterioration." Though needs remain, as local stations' conversion to digital broadcasting ramps down, CPB Digital funding for broadcast equipment will continue to diminish, and the Department of Commerce's Public Telecommunications Facilities Program (PTFP) can resume its role as the primary federal source for local station equipment funding.

Ready To Learn (FY 2011): CPB is requesting \$32 million in FY 2011 for Ready To Learn (RTL), a U.S. Department of Education program with a nearly 20-year proven record of using the power and reach of public television's children's programming to raise the reading levels of children ages 2-8 who live in high-poverty environments. Today, Ready To Learn is a partnership between CPB, PBS, WGBH (Boston), WTTW (Chicago), Sesame Workshop, leading researchers and public television stations nationwide. We strongly disagree with the Administration's proposed consolidation of RTL into an umbrella literacy program and instead believe that the difference this program has made on children's lives makes continued dedicated federal support imperative. An appropriation of \$32 million in FY 2011 will enable RTL content and accompanying materials to be created and tested on a faster timeline, and will enable more communities to become involved in existing station-based outreach activities.

Mr. Chairman and Ranking Member, thank you again for allowing CPB to submit this testimony. For nearly a half-century, public broadcasting has provided a safe place for millions of children to learn and unparalleled access to news and information; given voice to diverse points of view; and convened community dialogues. As the times have changed, so too have the technologies available to provide service to communities across our country. The challenge before us is how best to incorporate new capabilities into the public interest and service for all of our diverse citizenry, especially during these challenging economic times. With your continued support, we are ready to meet this challenge.

Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, and Education Concerning Programs in the United States Departments of Labor, Health and Human Services, and Education

By

**Corporation for Supportive Housing
Deborah DeSantis, President/CEO
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April 16, 2010

The Corporation for Supportive Housing (CSH) is a nonpartisan, nonprofit organization that helps communities build permanent supportive housing (PSH). We have offices in 12 states (California, Arizona, Texas, Illinois, Indiana, Ohio, Minnesota, Michigan, New Jersey, New York, Connecticut, Rhode Island) and the District of Columbia and have a presence in several others. We work with communities and states to reorient systems and leverage resources to create permanent supportive housing and end chronic homelessness. Although many people experiencing homelessness may only need rental or income supports to stay housed, there is a significant homeless population who needs intensive support services such as substance use treatment, mental health services, health care to manage chronic diseases, and case management services.

Most PSH providers receive at least a portion of the funds necessary to build or secure housing from the Department of Housing and Urban Development (HUD). Unfortunately, the Department of Health and Human Services has not made the same commitment to funding the services component of PSH. Organizations and local government agencies use a combination of state, local, foundation and privately raised funds to pay for the vital social services chronically homeless populations must have to stay housed. In order to build the PSH units needed to end chronic homelessness, the Department of Health and Human Services must increase its investment in local permanent supportive housing projects. To this end, CSH recommends the following:

- **Allocate \$120 million** for services for people experiencing homelessness within the Programs of Regional and National Significance (PRNS) accounts of both SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment. This includes the President's proposal for \$15.8 million to fund a joint HHS/HUD homeless program.
- **Increase** funding for the Projects for Assistance in Transition from Homelessness (PATH) program to **\$75 million**.
- **Add HCH**
- **Fund the Mental Health Services Block Grant (change name) at \$486.9, a \$66.1 million increase.**
- **Fund the Substance Abuse Prevention and Treatment Block Grant at \$1.929 billion, a \$150 million increase over FY 2009.**

Background

While HUD has made significant housing investments, there is a need for HHS to increase its

role in providing services resources for organizations to create permanent supportive housing. A majority of chronically homeless individuals live with serious mental illness, substance use disorders or chronic health conditions and to retain housing must have access services that require HHS expertise.

We know permanent supportive housing works. Over 80 percent of permanent supportive housing residents remain housed after the first year. In addition, work CSH has done targeting frequent users of health, jails or prisons illustrates the cost effectiveness of PSH. In California, we implemented the Frequent Users of Health Services Initiative (FUHSI). Through this study, we found that by placing clients into PSH we reduced their emergency room costs by 59 percent, reduced their inpatient days by an average of 62 percent and reduced average inpatient charges by 69 percent.

Our project targeting frequent users of jails and prisons has shown similar results. The Frequent Users of Services Enhancement (FUSE) Initiative is a joint project between the New York City Departments of Corrections and Homeless Services with assistance from the Department of Health and Mental Hygiene and the New York City Housing Authority. By assisting ex-offenders and providing permanent supportive housing to those who need it, NYC was able to help clients reduce jail stays by 33 percent and reduce mental health stays by 18 percent. For the 86 people served, the FUSE initiative was able to offset over \$3,500 in either jail or mental health costs per client.

In addition, there are several other subpopulations of those experiencing homelessness that would benefit from increased social services oriented funding. On a small scale, SAMHSA programs have targeted youth, veterans and families to ensure that all people experiencing homelessness who could benefit from mental health and substance use treatment can receive specialized support. However, without increased funding, communities will not be able to fully implement the permanent supportive housing model and continue to end homelessness in America.

Detailed Program Descriptions

SAMHSA Support Services for Permanent Supportive Housing Projects

CSH recommends allocating \$120 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.

Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient. The Administration obviously recognizes this and included a new initiative the Homeless and Services for Homeless Persons Demonstration. This joint HUD/HHS partnership is an important first step to integrating housing and services resources to ease organizations' ability to access federal funding. It also shows an understanding that housing and services is what is needed to end homelessness. This program is estimated to cost \$15.8 million. CSH asks that this initiative be fully funded in the appropriations process and that Congress include additional funds to ensure that current grantees can continue their work and new grants can be awarded. We look forward to working with Congress and the Administration to implement this initiative and ensure that it is properly evaluated.

Projects for Assistance in Transition from Homelessness (PATH)

CSH recommends that Congress increase PATH funding to \$75 million and adjust the funding formula to increase allocations for small states and territories.

PATH provides outreach to eligible consumers and ensures that those consumers are connected with mainstream services, such as Supplemental Security Income (SSI), Medicaid, and welfare programs.

PATH supported programs served over 135,007 people through outreach in fiscal year 2008. Of those for whom a diagnosis was reported, approximately 35 percent had schizophrenia and other psychotic disorders, and 47 percent had affective disorders such as depression. Also, 60 percent had co-occurring substance use disorders.

One issue that needs consideration, under the PATH formula grant, approximately 30 states share in the program's annual appropriations increases. The remaining states and territories receive the minimum grant of \$300,000 for states and \$50,000 for territories. These amounts have not been raised since the program was authorized in 1991. To account for inflation, the minimum allocation should be raised to \$600,000 for states and \$100,000 for territories. Amending the minimum allocation requires a legislative change. If the authorizing committees do not address this issue, we hope that appropriators will explore ways to make the change through appropriations bill language.

Community Health Centers and Health Care for the Homeless (HCH) Programs

CSH recommends \$2.602 billion in the Community Health Center program within Health Resource Services Administration. This would result in \$226.4 million for the HCH program, a \$36 million increase over FY 2009.

Persons living on the street suffer from health problems resulting from or exacerbated by being homeless, such as hypothermia, frostbite, and heatstroke. In addition, they often have infections of the respiratory and gastrointestinal systems, tuberculosis, vascular diseases such as leg ulcers, and hypertension.¹ Health care for the homeless programs are vital to prevent these conditions from becoming fatal. Congress allocates 8.7% of the Consolidated Health Centers account for HCH projects.

Mental Health Services Block Grant

CSH recommends that Congress appropriate \$486.9 million for the Community Mental Health Performance Partnership Block Grant.

The Mental Health Block Grant provides flexible funding to states to provide mental health services. Ending homelessness requires federal, state and local partnerships. Additional mental health funds will give states the resources to improve their mental health system and serve all people with mental health disorders better, including homeless populations. For example, block grant funds can be used to pay for services linked to housing for homeless people, thereby meeting the match requirements for projects funded through Shelter Plus Care or the Supportive Housing Program.

Substance Abuse Prevention and Treatment (SAPT) Block Grant

CSH joins our partners in recommending that Congress appropriate \$1.929 billion for the SAPT Block Grant.

¹ Harris, Shirley N, Carol T. Mowbray and Andrea Solarz. *Physical Health, Mental Health and Substance Abuse Problems of Shelter Users*. Health and Social Work, Vol. 19, 1994

The SAPT Block Grant is the primary source of federal funding for substance abuse treatment and prevention for many low-income individuals, including those experiencing homelessness. Studies have shown that half of all people experiencing homelessness have a diagnosable substance use disorder. States need more resources to implement proven treatment strategies and work with housing providers to keep homeless populations, especially chronically homeless populations, stably housed.

Conclusion

Homelessness is not inevitable. As communities implement plans to end homelessness, they are struggling to find funding for the services that homeless and formerly homeless clients need to maintain housing. The federal investments in mental health services, substance abuse treatment, employment training, youth housing, veterans' services, and case management discussed above will help communities create stable housing programs and change social systems which will end homelessness for millions of Americans.



COUNCIL FOR OPPORTUNITY IN EDUCATION

House Appropriations Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Fiscal Year 2011 Public Witness Record
April 16, 2010

Testimony of:

Dr. Arnold Mitchem, President
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On behalf of the thousands of low-income, first-generation students who participate in the Federal TRIO Programs, I respectfully request that the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies provide a \$150 million increase for TRIO in Fiscal Year 2011.

Currently TRIO serves approximately 840,000 low-income students in every state and territory in the nation. TRIO provides the critical academic, financial, social, and cultural supports for students that might not otherwise pursue or complete higher education. The services offered by TRIO are as vast as the participants themselves, which range from middle school students through doctoral candidates and include students with disabilities, military veterans, homeless and foster care youth, and working adults.

Despite the breadth of the programs' reach and depth of the programs' offerings, TRIO is only able to serve a fraction – approximately 11% – of the eligible population. Indeed, due to stagnant funding and increased costs, **today TRIO serves nearly 41,400 fewer students than it did in Fiscal Year 2005.**¹ Yet, the need for TRIO services is greater than ever. The current economic crisis has plunged many families into poverty and more and more people are returning to the classroom, thus increasing the need for the supports provided by the TRIO programs. There is also a particular need among our servicemen and -women who, upon return from their tours of duty overseas, require assistance in navigating the academic terrain and exploring the myriad of options and services available to them.

In examining the Fiscal Year 2011 budget proposal put forth by the Obama Administration, I was distressed at not only the level-funding request for TRIO, but also the move to pour millions and, in some cases, billions of dollars into unauthorized, untested education programs and initiatives, such as Investing in Innovation and Race to the Top. It is my sincere hope that the Subcommittee does not sacrifice the futures of thousands of low-income, first-generation students in the name of "innovation," but rather builds upon the success of the TRIO programs.

¹ Figures drawn from the "Funding Status" section for each TRIO program on the Department of Education's website at <http://www2.ed.gov/about/offices/list/ope/trio>.

Specific Needs in TRIO in Fiscal Year 2011

TRIO faces many significant challenges in the coming fiscal year due to the expiration of mandatory funds, alterations in program requirements, and the ever-evolving needs of our low-income, first-generation students. As such, the TRIO community formally requests a \$150 million increase for TRIO in Fiscal Year 2011, which would:

- **Sustain Upward Bound services for 12,000 students in approximately 200 programs across the country (\$57 million).** During the last grant competition for Upward Bound in 2007, several historic projects – including a disproportionate number of programs at historically black institutions – lost funding. At the time, Congress was crafting the College Cost Reduction and Access Act (CCRAA). Through this bill, Congress allocated \$57 million annually for Fiscal Years 2008-2011 to fund 187 new and existing Upward Bound projects. (Unlike typical TRIO funding, which is advanced-funded, these monies went into effect immediately. Therefore, the last year for which this funding is available is academic year 2010-2011.) Although the Department of Education has since announced plans to postpone the next Upward Bound competition until Fiscal Year 2012,² which will fund the 2012-2013 academic year, the fate of the nearly 200 Upward Bound programs supported by CCRAA remains unclear as that funding expires only two months into Fiscal Year 2012 on November 30, 2011. In order to preserve the current number of Upward Bound programs through academic year 2011-2012 (956 total), Congress must increase Upward Bound’s discretionary funding by \$57 million. (The Administration’s FY2011 budget request only requests enough funds to support 778 Upward Bound programs in academic year 2011-2012.) Otherwise, approximately 200 programs serving 12,000 students across the country will be lost.

- **Allow at least 15% of Talent Search students to receive services that promote their success in rigorous secondary curricula (\$35.8 million).** As a result of the changes mandated by Higher Education Opportunity Act, Talent Search programs will now be judged by the extent to which students successfully complete rigorous secondary school curricula. Presently, Talent Search services focus on information dissemination, counseling, and application assistance. The new requirement will change Talent Search from a “light-touch” program to one that must provide more intensive academic services. Practitioners in the TRIO community estimate that in order to get students through a rigorous curriculum, the per-student cost for Talent Search will need to increase from the current level of \$393 per student to at least \$1,200 per student. The increased cost would cover additional services such as in-school and after-school tutoring (both group and individual) as well as Saturday and summer academic enrichment programs. An additional \$35.8 million would allow for the provision of such services to at least 15% of currently enrolled Talent Search students. Without such an investment, many Talent Search programs will have no choice but to significantly reduce the number of students they serve or risk failure to meet this important objective.

² Letter from Daniel Madzellan, Delegated the Authority to Perform the Functions and Duties of the Assistant Secretary for Postsecondary Education, to all Potential Applicants for Grants under the FY 2011 Regular Upward Bound, Upward Bound Math and Science, and Veterans Upward Bound Programs Competitions (Apr. 2, 2010), available at <http://www2.ed.gov/programs/trioupbound/ub-competition.pdf>.

- **Expand the Educational Opportunity Center program by 30% (\$14.5 million).** President Obama has repeatedly emphasized the goal of having the highest proportion of college graduates in the world by the year 2020.³ In order to achieve such success, however, many of these new college graduates will have to be adults who return to school. For, even if every state reached the same levels of high school graduation and college enrollment for recent high school graduates as the highest performing states, we would not reach this goal without a renewed focus on enrolling and graduating adult learners.⁴ Yet, the United States is regressing in its enrollment of adult college students. Data demonstrate that the rate of college entry among adults aged 25-49 has declined by 20% since 1990 (6.5% vs. 8.1%); in fact, most students who begin college at age 25 or older never earn a degree or certificate.⁵ In fact, fewer than 20% of these students achieve such a credential.⁶ TRIO's Educational Opportunity Centers (EOCs) are among the few national initiatives focused on assisting adults in identifying, enrolling in, and paying for college. As EOCs specifically address the needs of un- and underemployed adults who seek to (re-)enter secondary and postsecondary education programs, their work will be even more critical in the immediate future. An increase of \$14.5 million will allow EOCs to offer services to more than 60,000 potential adult learners.

- **Restore services lost as a result of stagnant funding and provide opportunity for nearly 43,000 students (\$42.7 million).** TRIO funding has been stagnant for the last several years. Meanwhile, the cost of services and student needs have continued to increase. As stated above, TRIO programs have lost nearly 41,400 students since Fiscal Year 2005. An additional \$42.7 million would bring TRIO to its rightful place and allow thousands more low-income, first-generation students to receive TRIO services. In particular, such funding would:
 - **Improve retention, transfer, and graduation rates for Pell Grant recipients through the Student Support Services program.** Student Support Services (SSS) is the largest and most expansive national program promoting college persistence for low-income students. Congress created SSS to complement the Pell Grant and other financial aid programs in recognition of the fact that financial support alone is insufficient to ensure college completion.⁷ Unsurprisingly, students who participate in SSS perform better while in college – persisting from year to year, accruing more college credits, and earning higher grade point

³ Remarks of President Barack Obama to the Hispanic Chamber of Commerce, Delivered March 10, 2009, *available at* <http://www.whitehouse.gov/the-press-office/remarks-president-united-states-hispanic-chamber-commerce>.

⁴ Patrick J. Kelly, National Center for Higher Education Management Systems, *Improving the Re-Entry Pipeline: Non-Traditional Aged Adults Enrolling and Succeeding in Postsecondary Education* (Jan. 19, 2010).

⁵ *Id.*

⁶ *Id.*

⁷ In the Report Language to the 1980 Reauthorization of the Higher Education Act, Congress stated: "Without the information, counseling and academic services provided by the TRIO programs, disadvantaged students are often unable to take advantage of the financial assistance provided by the other Title IV programs." H.R. Rep. No. 96-520, at 25 (1980), *as reprinted in* 1980 U.S.C.C.A.N. 3141.

averages⁸ – and graduate at higher rates than other low-income students.⁹ By expanding SSS, Congress can address the unmet needs of even more low-income college students and help ensure that they graduate from college. Such support will also shore up the nation's significant investments in the Pell Grant program as SSS students are virtually by definition Pell Grant recipients.

- **Engage high school students in math and the sciences, while boosting their chances of enrolling in college, through the Upward Bound Math-Science program.** Upward Bound Math-Science has had tremendous success in fostering interest and cultivating talent in the critical areas of math and science. Recent data show that, nationally, 86.5% of students who participated in an Upward Bound Math-Science program go directly to college after graduating from high school.¹⁰ This is in sharp contrast to the fact that only 41% of low-income high school students go onto college.¹¹ If the United States is to emerge as a global leader in such fields, it must increase funding for this program to help produce the next generation of scholars in these areas.
- **Increase the number of doctoral degrees earned by low-income, first-generation students from underrepresented backgrounds through McNair Postbaccalaureate Achievement.** TRIO's Ronald E. McNair Postbaccalaureate Achievement program encourages and prepares low-income, first-generation, and minority students for doctoral study by providing research opportunities and faculty mentoring. While the number of racial and ethnic minorities earning doctoral degrees is on the rise, as recently as 2006 they comprised just 15.7% of all doctoral recipients in the United States.¹² Therefore, the need for increased support for underrepresented students in postgraduate education programs is clear.
- **Help our nation's veterans pursue higher education upon their return home.** Since 1972, Veterans Upward Bound (VUB) has been serving the educational needs of our nation's veterans by assisting them in identifying, enrolling in, and paying for college and providing intensive skill development for veterans to help

⁸ Bradford, C., Muraskin, L., Cahalan, M., & Rak, R. (1997). *National study of Student Support Services: Third-year longitudinal study of results and program implementation study update*. Washington, DC: U.S. Department of Education.

⁹ In recent years, SSS students had 31-32% graduation rates (versus the 21% and 9% rates of Pell Grant and non-Pell Grant students, respectively). Sources: U.S. Department of Education, National Center for Education Statistics, 1995-96 Beginning Postsecondary Students Longitudinal Study, Second Follow-up (BPS:96/01); U.S. Department of Education, *Federal TRIO Programs, Student Support Services, Performance and Efficiency Measure Results: 2004-05*; Mortenson, *Bachelor's Degree Attainment by Age 24 by Family Income Quartiles, 1970-2006 (2008)*, retrieved from www.postsecondary.org.

¹⁰ U.S. Department of Education, Federal TRIO Programs, Upward Bound Annual Performance Reports (APRs): 2000-2001 through 2005-2006.

¹¹ Tom Mortenson, *Bachelor's Degree Attainment by Age 24 by Family Income Quartiles, 1970-2006 (2008)*, retrieved from www.postsecondary.org.

¹² U.S. Department of Education, National Center for Education Statistics, *Doctor's degrees conferred by degree-granting institutions, by sex, race/ethnicity, and field of study: 2006-07*, available at http://nces.ed.gov/ipeds/data/ipeds_data_query.asp?table=08_291. (This figure excludes non-resident alien doctoral recipients.)

them successfully transition from military service into postsecondary education and the workforce. Yet, there are currently only 48 VUB projects in the country, located in 31 states and Puerto Rico. It is quite troubling that there is only one VUB project located in each of the five states with the largest veteran populations – California, Florida, Texas, New York, and Pennsylvania. Nationally, VUB has a strong record of aiding its participants in going to college. According to the National Association of Veterans Upward Bound Project Personnel, last year 67% of the veterans that completed Veterans Upward Bound entered into a postsecondary education program. With ongoing conflicts abroad and large numbers of veterans returning home, the need for services to support our servicemen and -women is greater than ever.

The needs within TRIO in the coming fiscal year are great as are the economic needs of the country. However, in addition to supporting the needs of today's low-income, first-generation students, the Subcommittee would help ensure America's financial future by investing in TRIO as it is one of the best mechanisms for helping low-income students earn college degrees. Over the course of a person's working life (age 25-65), a college graduate is worth \$472,000 in tax revenues.¹³ This is in contrast to the revenues generated by a high school graduate, which is only \$260,000.¹⁴ When you factor in the revenues generated by a high school graduate compared with a student that earned a bachelor's degree, it would take only 708 college graduates (over their lifetimes) to pay for a \$150 million investment in TRIO.

As Congress begins the important work of setting federal spending levels in the coming year, the TRIO community strongly encourages this Subcommittee to appropriate a \$150 million increase for TRIO in Fiscal Year 2011. (This would amount to a total appropriation of \$1.003 billion.) To do otherwise would only continue the chokehold that is slowly squeezing the life from these invaluable programs.

I thank you for your attention to this matter and look forward to working together with the Members of the Subcommittee to ensure equal educational opportunity for all American students.

¹³ Figures derived from data provided in the College Board's 2005 document, *Education Pays Update, A Supplement to Education Pays 2004: The Benefits of Higher Education for Individuals and Society*, which is available online at http://www.collegeboard.com/prod_downloads/press/cost05/education_pays_05.pdf.

¹⁴ *Id.*

COUNCIL OF ACADEMIC FAMILY MEDICINE

Society of Teachers of Family Medicine
 Association of Departments of Family Medicine
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Written Testimony for the Record
 House Appropriations Labor/HHS/Education and Related Agencies Subcommittee
 April 15, 2010

FY 2011 FUNDING REQUESTS

Department of Health and Human Services
 Workforce Commission and associated centers

Health Resources and Services Administration (HRSA)

Title VII primary care cluster (Section 747 of Public Health Service Act (PHS))
 Teaching Health Center development grants (Section 749A. of PHS Act)
 Rural Physician Training Grants (Section 749B. of PHS Act)

Agency For Healthcare Research And Quality (AHRQ)

Agency funding
 Primary Care Extension Program (Section 399W of PHS Act)

Dear Mr. Chairman,

On behalf of the Council of Academic Family Medicine (CAFM), we are pleased to submit testimony on behalf of several programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ).

We are very pleased to have supported the Patient Protection and Affordable Care Act (PPACA) and to see it enacted into law. We appreciate Congress's efforts to extend health care coverage to all and are pleased that the law contains significant efforts to support and sustain programs that will help produce a workforce needed to take care of the nation. As the law acknowledges, there is much that must be done to support primary care production and nourish the development of a high quality, highly effective primary care workforce to serve as a foundation for our health care system.

COUNCIL OF ACADEMIC FAMILY MEDICINE

Society of Teachers of Family Medicine
 Association of Departments of Family Medicine
 Association of Family Medicine Residency Directors
 North American Primary Care Research Group

Health Care Reform Requires a Robust Primary Care Workforce

The PPACA contains many measures to address the need for more primary care physicians. As you know, increased access for patients in terms of insurance coverage is critical, but not sufficient to resolve the growing shortage of primary care physicians. In fact, increased coverage, without increased numbers of primary care physicians, is a recipe for disaster. The implementation of the 2006 Massachusetts health care reform law demonstrated that universal coverage will overwhelm a health care system with too few primary care physicians, especially, family physicians. Addressing the shortage of primary care physicians requires a long-term commitment to train an appropriate number of these essential health care providers. We must increase our investment in effective programs that encourage medical students to enter primary care specialties.

Toward that end, there are several programs and agencies whose domain is critically important to producing more primary care physicians and providing them with the tools to support high quality care. It is those programs and agencies that come under this subcommittee's jurisdiction and that this testimony addresses.

Primary Care Training and Enhancement

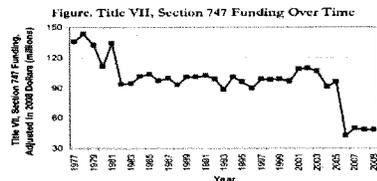
Section 747 of the Public Health Service Act has a long history of providing necessary funding for the training of primary care physicians. In each reauthorization Congress has modified the program to obtain certain key goals. The current authorization gives direction to HRSA to recognize and prioritize training that will support development of expertise in new competencies, including those relevant to providing care through patient-centered medical homes, development of infrastructure within primary care departments for the improvement of clinical care and research critical to primary care delivery, as well as innovations in team management of chronic disease, integrated models of care, and transitioning between health care settings. One new area of endeavor is the integration of academic administrative units within a school of medicine to promote team based care and true primary care production. This provision has a separate, additional authorization of \$750,000.

The Advisory Committee on Training in Primary Care Medicine and Dentistry recommends \$235 million for these programs (including dentistry which has subsequently been dropped from this cluster). Other key advisory bodies such as the Institute of Medicine (IOM) and the Congressional Research Service (CRS) call for increased funding. The IOM (Dec. 2008) pointed to the drastic decline in Title VII funding and described these health professions workforce training programs as "an undervalued asset." The Congressional Research Service found that reduced funding to the primary care cluster has had a negative impact on the effectiveness of the programs during a time when more primary care is needed (February 2008).

According to the Robert Graham Center, (Title VII's decline: Shrinking investment in the primary care training pipeline, Oct., 2009), "the number of graduating U.S. allopathic medical students choosing primary care declined steadily over the past decade, and the proportion of minorities within this workforce remains low." Unfortunately, this decline coincides with a decline in funding of primary care training funding – funding that we know is associated with increased primary care physician production and practice in underserved areas.

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The report goes on to say that "the nation needs renewed or enhanced investment in programs like Title VII that support the production of primary care physicians and their placement in underserved areas." This situation is only exacerbated by the wonderful explosion of people who will gain insurance coverage under the new health care reform law. Given the tremendous need,

We urge the Committee to provide a FY 2011 appropriation of \$170 million for the Title VII Section 747 Primary Care Training and Enhancement, including the Integrative Academic Administrative Units program, as authorized by the *Patient Protection and Affordable Care Act*. We also recommend an appropriation of at least \$600 million for all of the Health Professions Training Programs authorized under Title VII of the Public Health Services Act.

Rural Physician Training Grants

We were pleased that the PPACA included a new program as part of Title VII of the Public Health Service Act, Section 749B, entitled the "Rural Physician Training Grants" program. It is intended to increase the supply of rural physicians by authorizing grants to medical schools which establish or expand rural training. The program would provide grants to produce rural physicians of all specialties. It would help medical schools recruit students most likely to practice medicine in underserved rural communities, provide rural-focused training and experience, and increase the number of medical graduates who practice in underserved rural communities.

According to a July, 2007 report of the Robert Graham Center (*Medical school expansion: An immediate opportunity to meet rural health care needs*), data show that although 21 percent of the U.S. population lives in rural areas, only 10 percent of physicians practice there. The Graham Center study describes the educational pipeline to rural medical practice as "long and complex." There are multiple tactics needed to reverse this situation, and this grant program includes several of them. Strategies to increase the number of physicians practicing in rural areas include "increasing the number of rural-background students in medical school, selecting the "right" students and giving them the "right" content and experiences to train them for rural practice." This is exactly what this grant program is designed to do.

We request the Committee provide the fully authorized amount of \$4 million in FY 2011 for Title VII Section 749B Rural Physician Training Grants.

Teaching Health Centers Development Grants

One of the more creative programs to come out of the health care reform bill as it relates to workforce is the establishment of Teaching Health Centers (THCs). These are community health centers or other similar venues that sponsor residency programs and provide residents with their ambulatory training experiences in the health center. This training in the community, rather than

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solely at the hospital bedside is one of the hallmarks of family medicine training. In fact, numerous family medicine residency programs currently align with health centers to provide residents with their ambulatory continuity training in these settings. However, payment issues have always caused a tension and struggle between the hospital, which currently receives reimbursement for residents it sponsors when they train in the hospital, and programs that require training in non-hospital settings. This program is designed to provide residency programs and community health centers grant funding to plan for a transition in sponsorship, or the establishment of new programs.

It allows the Secretary to award grants to THC's (community based ambulatory patient care centers that operate a primary care residency program; listed as FQHC, rural health clinic, community mental health center, health center operated by Indian Health Service, or a center receiving Title X grants) to establish new accredited or expanded primary care residency programs. We were pleased that the *Patient Protection and Affordable Care Act* authorized a mandatory appropriations trust fund of \$230 million over five years to fund the operations of Teaching Health Centers. However, if this program is to be effective, there must be funds for the planning grants to establish newly accredited or expanded primary care residency programs.

We recommend the Committee appropriate the full authorized amount for the new Title VII Teaching Health Centers development grants of \$50 million for fiscal year 2011.

AHRQ

Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians care for on a daily basis is currently lacking. Primary care physicians are in the best position to design and implement research of the common clinical questions confronted in practice. AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. While targeted funding increases in recent years have moved AHRQ in the right direction, more core funding is needed to help AHRQ fulfill its mission.

The Institute of Medicine's report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001) recommended a much larger investment in AHRQ. It recommended \$1 billion a year for AHRQ to "develop strategies, goals, and action plans for achieving substantial improvements in quality in the next 5 years..." AHRQ is critical to retooling the American health care system.

We support the President's budget request for AHRQ in FY 2011 of \$611 million. With the inclusion of new programs authorized under the PPACA, we support a total appropriations level of \$731 million for the Agency.

Primary Care Extension Program

One of the most exciting new programs to be included in the new health care reform law is one that utilizes the experience of the United States Agriculture Extension Service as its model. This new program, under Title III of the Public Health Service Act, is designed to support and assist primary care providers with the adoption and incorporation of techniques to improve community health. As the authors of an article describing this new concept (*JAMA*, June 24, 2009) have stated, "To successfully redesign practices requires knowledge transfer, performance feedback,

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facilitation, and HIT support provided by individuals with whom practices have established relationships over time. The farming community learned these principles a century ago. Primary care practices are like small farms of that era, which were geographically dispersed, poorly resourced for change, and inefficient in adopting new techniques or technology but vital to the nation's well-being."

Congress agreed with the authors that "practicing physicians need something similar to the agricultural extension agent who was so transformative for farming," and authorized this program at \$120 million for FY2011 and 2012.

We support the President's budget request for AHRQ in FY 2011 of \$611 million. In addition, since the \$611 million does not include this newly-passed provision, we request the Committee provide AHRQ with an additional \$120 million for the Primary Care Extension program authorized by the health reform law, bringing the total request to \$731 million.

Workforce Commission

We have recognized the need, and called for a national commission on health workforce issues for many years. We are pleased that the PPACA established a National Health Care Workforce Commission to provide "analysis of, and recommendations for, eliminating the barriers to entering and staying in primary care, including provider compensation." We also recognize the importance of the National Center for Health Care Workforce Analysis as well as State and Regional Centers for such analysis. PPACA authorizes such sums as necessary to establish the Commission as well as \$8 million in planning grants and \$150 million for implementation grants. The National Center was authorized at \$7.5 million annually and the State and Regional Centers were authorized at \$4.5 million annually.

We recommend the Committee fully fund the National Health Care Workforce Commission, the National and State and Regional Centers for Health Care Workforce Analysis in FY 2011.

We appreciate the work of the Committee in making difficult choices when funding many critical programs. We caution the committee not to ruin the positive impact of health care reform by not supporting the complementary programs that are so necessary to its success.



COUNCIL ON SOCIAL WORK EDUCATION

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**Testimony for Fiscal Year 2011 regarding the
 Departments of Education and Health and Human Services**

Submitted to the Subcommittee on Labor,
 Health and Human Services, Education, and Related Agencies
 Committee on Appropriations
 United States House of Representatives
 April 16, 2010

Submitted by
 Dr. Julia M. Watkins, Executive Director
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On behalf of the Council on Social Work Education, I am pleased to offer this written testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for inclusion in the official Committee record. I will focus my testimony on the importance of fostering a skilled, sustainable, and diverse social work workforce through professional education, training and financial support programs at the Department of Health and Human Services and the Department of Education.

The Council on Social Work Education (CSWE) is a nonprofit national association representing more than 3,000 individual members as well as 650 graduate and undergraduate programs of professional social work education. Founded in 1952, this partnership of educational and professional institutions, social welfare agencies, and private citizens is recognized by the Council for Higher Education Accreditation (CHEA) as the sole accrediting agency for social work education in the United States. Social work education focuses students on leadership and direct practice roles helping individuals, families, groups, and communities by creating new opportunities that empower people to be productive, contributing members of their communities.

Vulnerable populations from all walks of life—such as children and adults with physical or mental disabilities, those living in poverty, trauma victims, aging individuals, returning veterans, individuals under stress or facing coping challenges both temporary and permanent, and segments of society needing assistance to adjust to changing circumstances or overcome injustices—are faced with hurdles which for some cannot be overcome alone. Social workers help vulnerable populations in society be as healthy and productive as possible by working with them to navigate societal and personal challenges. Social workers are employed in schools, hospitals, VA facilities, rehabilitation centers, social service locations, child welfare organizations, assisted living centers, nursing homes, and faith-based organizations.

The ability to recruit and retain social workers poses a significant challenge to the success of the profession and ultimately our ability to serve vulnerable populations. This is true across all

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sectors (public and private), at all levels (from bachelor's to the doctoral level), and in all fields of practice (child welfare, public health, mental health, geriatrics, veterans, etc.).

The nation requires a social work workforce that is skilled, diverse, and able to keep pace with demand. However, the U.S. Bureau of Labor Statistics estimates that employment for social workers is expected to grow faster than the average for all occupations through 2018, particularly for social workers specializing in the aging population and working in rural areas. In addition, mental health and substance abuse social workers are expected to grow by almost 20 percent over the 2008-2018 decade, with social workers specializing in substance abuse experiencing strong demand as people are increasingly placed in treatment programs instead of prison systems. Further, "[the] growing elderly population and the aging baby boom generation will create greater demand for health and social services, resulting in rapid job growth among gerontological social workers."¹

While recruitment and retention can be a significant challenge for many professions, especially those dealing with public health and the delivery of social services, the problem is exceptionally widespread for social work. Recruitment into the social work profession faces many obstacles, the most prevalent being low wages coupled with high educational debt. For example, the median annual wage for child, family, and school social workers in May 2008 was \$39,530, while the wage for mental health and substance abuse social workers was \$37,210. Further, while a bachelor's degree (BSW) is necessary for most entry-level positions, a master's degree (MSW) is the terminal degree for social work practice, which significantly contributes to the debt load of social work graduates entering careers with low starting wages. According to the 2007-2008 National Postsecondary Student Aid Study conducted by the National Center for Education Statistics at the U.S. Department of Education, 72 percent of students graduating from MSW programs incurred debt to earn their graduate degree. The average debt was approximately \$35,500. The percentage of MSW students borrowing money is 17 percent higher than the average for all master's degrees and the amount borrowed is approximately \$5,000 higher than the average for all master's degrees. These difficult realities have made recruitment and retention of social workers an ongoing challenge.

The below recommendations for Fiscal Year (FY) 2011 would help to ensure that we are fostering a sustainable, skilled, and diverse workforce that will be able to keep up with the increasing demand for social work services.

Department of Health and Human Services

The agencies within the Department of Health and Human Services (HHS) provide professional education, training, fellowship, and loan repayment opportunities to help recruit and retain social workers in the profession. CSWE urges the Committee's support for the following HHS programs:

Minority Fellowship Program, Substance Abuse and Mental Health Services

¹ U.S. Bureau of Labor Statistics, Occupational Outlook Handbook, 2010-11 Edition: Social Workers, <http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm> (March 2010).

Administration (SAMHSA) – The goal of the SAMHSA Minority Fellowship Program (MFP) is to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental health and substance abuse field. According to SAMHSA, “Minorities make up approximately one fourth of the population, but only about 10 percent of mental health providers are ethnic minorities.” CSWE has been a grantee of this critical program for years, administering funds to exceptional minority social work students. Together with a program at the National Institute of Mental Health (see below for more information), CSWE has supported over 500 minority fellows since the program’s inception, with about two-thirds of those students having gone on to receive their doctoral degrees. *For FY 2011, CSWE urges the Committee to appropriate \$7.5 million to the SAMHSA Minority Fellowship Program.* This would include \$6.882 million for the Center for Mental Health Services, where the majority of MFP funds are administered; \$71,000 for the Center for Substance Abuse Prevention; and \$547,000 for the Center for Substance Abuse Treatment.

The program has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage counselors since its inception. Still, the program continues to struggle to keep up with the demands that are plaguing our health professions. Severe shortages of mental health professionals often arise in underserved areas due to the difficulty of recruitment and retention in the public sector. Nowhere are these shortages more prevalent than in Indian Country, where mental illness and substance abuse go largely untreated and incidences of suicide continue to increase. Studies have shown that ethnic minority mental health professionals practice in underserved areas at a higher rate than non-minorities. Furthermore, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.

The \$7.5 million request would be used to substantially increase access to professional education and training for additional minority mental health and substance abuse professionals, in turn helping to ensure that underserved minority populations receive the mental health and substance abuse services they so desperately need. President Obama’s FY 2011 budget request includes flat funding for the MFP at about \$4.9 million. Funding the MFP at \$7.5 million would directly encourage more social workers of minority backgrounds to pursue doctoral degrees in mental health and substance abuse and will turnout more minority mental health professionals equipped to provide culturally competent, accessible mental health and substance abuse services to diverse populations.

Institutional Research Training Program in Social Work (T32), National Institute of Mental Health (NIMH) – The National Institute of Mental Health (NIMH) within the National Institutes of Health (NIH) initiated a training program in the 1970s that sought to increase the number of minority doctoral students focusing their research in mental health. Like the SAMHSA program mentioned above, CSWE has ably administered a grant from NIMH for many years, which provides mentored training opportunities to minority social work researchers. The social work profession depends on culturally-competent and culturally-relevant research to assess the circumstances facing vulnerable populations and the needs of those populations to succeed in their circumstances, evaluate the accessibility to and effectiveness of existing social

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services, and determine best practices for social work educators and practitioners for serving the community. While this program has been successful in enhancing diversity among social workers conducting mental health research and has allowed more underrepresented social work researchers to be brought into the fold as NIH investigators, NIMH recently announced its plan to cancel the program in 2010 and transition the funds to support the traditional, non-diversity-focused T32 training program at NIMH. CSWE is very concerned about the implications of this decision, both on the diversity of researchers at NIMH and what we feel could lead to an absence of social work research at NIMH. *We urge the Committee to encourage NIMH to take the necessary steps to enhance diversity of the NIH/NIMH grant pool and express to NIMH the value and importance of social work research to the study of mental health.*

Title VII and VIII Health Professions Programs, Health Resources and Services Administration (HRSA) – The Title VII and Title VIII (nursing) health professions programs at HRSA provide financial support for education and development of the health care workforce. The emphasis of these programs is on improving the quality, diversity, and geographic distribution of the health professions workforce, and is currently the only federal program to do so. These programs provide loans, loan guarantees and scholarships to students, and grants to institutions of higher education and non-profit organizations to help build and maintain a robust health care workforce. Social work students and practitioners are eligible for Title VII funding. We thank the Committee for recognizing the value of these programs by providing an additional \$200 million for the Title VII and Title VIII programs in the *American Recovery and Reinvestment Act of 2009* (P.L. 111-5). *CSWE urges the Committee to provide \$600 million for the Title VII and Title VIII health professions programs for FY 2011.*

In addition, the *Patient Protection and Affordable Care Act* (P.L. 111-148) recently authorized a number of new programs within Title VII. In particular, CSWE urges the Committee to provide first-time funding for the Mental and Behavioral Health Education and Training Grants program, which would provide grants to institutions of higher education (schools of social work and other mental health professions) for faculty and student recruitment and professional education and training. *The law authorizes \$8 million for training in social work for FY 2011. CSWE urges the Committee to appropriate the full amount.* As stated earlier, mental health and substance abuse social work is expected to grow by nearly 20 percent over the next decade. Programs like this will prove invaluable in encouraging more people to enter careers specializing in mental and behavioral health.

Department of Education

CSWE urges the Committee to support the following programs at the Department of Education:

Loan Forgiveness for Service in Areas of National Need Program – The *Higher Education Opportunity Act of 2008* (P.L. 110-315) created the Loan Forgiveness for Service in Areas of National Need program; however, the program has not yet been funded. CSWE applauds Congress for expanding the Income Based Repayment (IBR) program in the recently passed *Student Aid and Fiscal Responsibility Act/Reconciliation Act of 2010* (P.L. 111-152), but urges Congress to fund the Loan Forgiveness for Service in Areas of National Need program, which

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unlike IBR would offer immediate relief for qualifying social workers. This program applies to full-time workers who are employed in areas of national need, such as social workers working in public or private child welfare agencies or mental health professionals with at least a master's degree in social work. ***CSWE urges full funding for this program for FY 2011.***

American Graduation Initiative – While President Obama's American Graduation Initiative (AGI) was not ultimately funded in the *Student Aid and Fiscal Responsibility Act/Reconciliation Act of 2010* (P.L. 111-152), CSWE urges the Committee to appropriate funding to begin this important initiative in FY 2011. The initiative seeks to produce 5 million additional community college graduates by 2020, create a Community College Challenge Fund to provide competitive grants for reform (including expansion of course offerings, dual enrollment at high schools and universities, and transfer of credit), fund innovative strategies to promote college completion, modernize community college facilities, and create a new online skills laboratory. For many professions that are in high demand and for which shortages exist, like social work, four-year degrees are required to enter the workforce. CSWE is interested in enhancing the relationships between schools of social work and two-year programs to provide a more seamless transition from community college to four-year social work programs as a way to help address shortages in the social work profession. ***CSWE urges the Committee to invest in AGI in FY 2011.***



May 14, 2010

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Dear Members of the House Appropriations Committee:

I would like to take this opportunity to speak up against the idea of a fee-based Voluntary Protection Programs (VPP). As an employee at a VPP site, I believe that this will be detrimental to the integrity of the program and the culture of pro-active safety and health beyond compliance that it currently instills.

In his report to the House Budget Committee on March 4, 2010, Congressman George Miller (D-CA), chair of the House Committee on Education and Labor, supported the Department of Labor's (DOL) shift of funding and resources away from VPP in favor of enforcement. He proposed to fund VPP *"through a user fee, and plans to work on establishing authority for augmenting the OSHA budget through a fee based system"*. Funding VPP through a user-fee system for certification would take away from the independent verification of our safety and health management system because it would lead to a direct relationship between number of VPP sites and fees paid to the government. Some repeated concerns expressed by many of our 921,000 American workers now covered by VPP include:

- Industry directly funding the government to perform part of its required function under the OSH Act.
- Creating the perception that employers are "buying" the VPP flag.
- Creating a situation where employers can be perceived as purchasing "an exemption from routine OSHA inspections."
- Fees for VPP deterring small businesses from participating.
- Charging sites for participation in VPP despite of what VPP sites voluntarily give in the form of mentoring, outreach, assist visits, funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national conferences.
- Paying a fee reduces VPP to a government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride.

In a way, America's worksites would be directly funding the Occupational Safety and Health Administration (OSHA) to perform its functions as required by the OSH Act and private industry and special interests' funding the Federal Government is against the law. The Occupational Safety and Health Act of 1970 requires that 13 objectives be

accomplished. Only **one** of the 13 objectives is enforcement, **two** are standard setting, and **three** are directly related to the development of cooperation between employer and employee to establish a safe workplace – exactly what the founders of OSHA VPP established the program to accomplish. Congress and DOL taking actions to shift funding from VPP in favor of enforcement is not a return to OSHA's 'roots in enforcement,' only an Agency ignoring 12 other mandates from Congress and asking American's worksites to provide that funding through a user fee-based system to pay the agency to implement all the requirements under the OSH Act. Unlike many fee-based certification programs, VPP is a comprehensive workplace safety and health management system that is built on cooperation among workers, employers and government. If the DOL backs away from the partnership, it diminishes the program instead of strengthening OSHA's partnership with corporate America in an effort to push beyond outdated standards.

While I continue to support firm and fair enforcement as a necessary tool to reach worksites that are not voluntarily improving their safety and health programs, I firmly believe that there is clear evidence that 40 years of enforcement has failed in producing the necessary culture shift that is required to achieve measurable and sustainable improvements in the protection of the American workforce and to keep American businesses competitive in a global marketplace.

It is clear that 40 years of enforcement have left America's small businesses - collectively the largest employers and source of future "good jobs" – lacking. Under any administration, OSHA's dealings with America's small businesses have either been 'hands-off' or "penalize to closure," because those are the only two options in an Agency focusing solely on enforcement. In recent years, smaller worksites have increased significantly within VPP, growing from 28 percent of VPP sites in 2003 to 39 percent in 2008, thanks to innovations such as mentoring and the VPP Challenge Program. These innovations are keeping employees safer at worksites that traditionally would not see an OSHA compliance inspection or, if fined, might have to go out of business or at the very least provide lay-off notices to employees to cover the citation and associated penalties. These worksites have seen the value in a proactive safety program, such as VPP, that is saving companies and taxpayers money.

In 2007, OSHA evaluated the benefits of the VPP and reported that Federal Agency VPP participants, in OSHA, the Department of Energy (DOE), the Department of Defense (DOD), and the National Parks Service, to name a few, saved the government more than \$59 million by avoiding injuries and the private sector VPP participants saved more than \$300 million. These funds are a return on investment that are funneled into new equipment, expanding production, creating 'good jobs,' keeping 'good jobs,' and voluntarily mentoring other work sites in the community to learn the value of VPP and keeping American workers safe. That money should not be used to fund the Federal Government to perform its required obligations under the OSH Act.

The Federal Government already benefits from its involvement in VPP and from the private sector's participation in VPP, such as:

- The \$59 million saved by Federal Agency participants in VPP is money that demonstrates fiscal responsibility and cost avoidance and allows for the reallocation of resources to the mission of the Agency.
- The U.S. Department of Labor's Safety, Health, and Return-to-Employment (SHARE) initiative was launched in 2004 to help the Federal Government in reducing injury and illness cases and lost production day rates, and to substantially improve timely filing of injury and illness notices. Agencies that adopted VPP achieved greater and sustainable improved performance in the SHARE initiative and want to expand the VPP throughout their operations.
- The DOD, with 31 VPP sites, has seen a substantial return on investment by adopting VPP in terms of reduced injuries and illnesses and a strong improvement in maintaining mission-readiness.
- In 2003, the DOE Appropriations language noted a dramatic improvement in the safety and health within the Complex and challenged DOE to *"maintain worker safety and health performance at least to levels seen in 2002,"* that performance was achieved by 21 VPP sites in the DOE Complex.
- The cost avoidance in workers compensation for a single contractor in the DOE Complex was a \$3 million cost reduction in three years by working toward and installing VPP. That was \$3 million in taxpayers' money redirected to the DOE mission, just by preventing worker injuries.
- OSHA also directly benefits by reducing employee injuries and illnesses at three of its Regional Field Offices that are VPP.
- Additionally, when workplaces make the significant commitment to safety required by VPP, it allows OSHA to focus its resources of enforcement where they are most needed – on those companies that *"don't get it"* – as stated by the Secretary of Labor.

Recent tragic events in the American workplace cause us great concern, such as the mining disaster in West Virginia and the refinery explosion in Washington State. These events remind us that when we continue to return to only one tool in OSHA's toolbox to achieve a safe workplace – and that tool is enforcement – that we will never achieve, as a nation, the necessary culture, mindset and attributes necessary to protect our most valued asset – the American worker. Each of these tragic examples, worksites and employers had received routine inspections and citations from OSHA and the Mine Safety & Health Administration (MSHA) compliance officers. Those visits were routine, on average five inspections in the past seven years, all with citations and large fines. These events demonstrate what 40 years of enforcement have achieved. Why would recapitulating this lesson return different results? Would more workers go home to their families at night?

Instead, what if on just one of those OSHA or MSHA inspections the compliance officer would have recommended the company enter into the VPP Challenge Program?

- *What if*, through OSHA's VPP, one of those companies had learned the value, in human preservation and financially, of preventing accidents and avoiding costs and impacts to the bottom line?
- *What if* one of those companies was the first in their industry to demonstrate that safety and profitability are achievable together?
- *What if* others in their industry took notice and started to embrace the same ideas and sought to achieve VPP status in order to maintain a competitive edge?

Would more workers then go home to their families at night?

I ask you to speak out against the idea of a fee-based Voluntary Protection Programs and to ensure the continued success of OSHA's VPP as a cooperative program by reinstating direct and continued funding in the DOL budget. Highly successful cooperative programs like VPP should be funded and expanded if OSHA is to assist American businesses in achieving the necessary cultural change required to maintain and protect American workers, which is a proven method that supports OSHA's mission. I ask that you provide full funding in the DOL budget for VPP and include specific Appropriations language to restore and direct the Agency to fund, resource load and conduct VPP assistance, application evaluations, onsite re-approvals and new onsite evaluations to the levels equal to or greater than those achieved in 2005.

Sincerely,

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STATEMENT OF

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**SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**

**REGARDING FY11 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND
HUMAN SERVICES**

APRIL 16, 2010

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the 1.4 million Americans living with Crohn's disease and ulcerative colitis. My name is Gary Sinderbrand and I have the privilege of serving as the Chairman of the National Board of Trustees for the Crohn's & Colitis Foundation of America (CCFA). CCFA is the leading voluntary organization in the United States that is dedicated to finding a cure for Crohn's disease and ulcerative colitis, chronic and often debilitating digestive diseases -- collectively known as inflammatory bowel diseases (IBD).

Let me express at the outset how appreciative we are for the leadership this Subcommittee has provided in advancing funding for the National Institutes of Health. Hope for a better future for our patients lies in biomedical research and we are so grateful for the recent investments that you have made in this critical area.

Mr. Chairman, Crohn's disease and ulcerative colitis are devastating inflammatory disorders of the digestive tract that can cause severe abdominal pain, fever and intestinal bleeding. Complications include arthritis, osteoporosis, anemia, liver disease and colorectal cancer. We do not know their cause, and there is no medical cure. They represent the major cause of morbidity from digestive diseases and forever alter the lives of the people they afflict -- particularly children. I know, because I am the father of a child living with Crohn's disease.

Seven years ago, during my daughter, Alexandra's sophomore year in college, she was taken to the ER for what was initially thought to be acute appendicitis. After a series of tests, my wife and I received a call from the attending GI who stated coldly: Your daughter has Crohn's disease, there is no cure and she will be on medication the rest of her life. The news froze us in our tracks. How could our vibrant, beautiful little girl be stricken with a disease that was incurable and has ruined the lives of countless thousands of people?

Over the next several months, Alexandra fluctuated between good days and bad ones. Bad days would bring on debilitating flares which would rack her body with pain and fever as her system sought equilibrium. Our hearts were filled with sorrow as we realized how we were so incapable of protecting our child.

Her doctor was trying increasingly aggressive therapies to bring the flares under control. Asacol, steroids, mercaptopurine, methotrexate and finally Remicade. Each treatment came with its own set of side effects and risks. Every time A would call from school, my heart would jump before I picked up the call in fear of hearing that my child was in pain as the flares had returned. Ironically, the worst call came from one of her friends to report that A was back in the ER and being evaluated by a GI surgeon to determine if an emergency procedure was needed to clear an intestinal blockage that was caused by the disease. Several hours later, a brilliant surgeon at the University of Chicago, removed over a foot of diseased tissue from her intestine. The surgery saved her life, but did not cure her. We continue to live every day knowing that the disease could flare at any time with devastating consequences.

From the point of hearing the news, I refused to accept the fact that this disease could not be cured. As I studied all the relevant data I could find, I reached out to the organization that seemed to be repeatedly mentioned, the Crohn's & Colitis Foundation. This organization is leading the fight in research, education and support on behalf of the 1.4 million Americans that suffer from these illnesses.

I made a pest of myself at the National office seeking knowledge about how the fight was being staged. The more I learned the more I believed that we could do better. I was invited to join the national board and seven years later, I have the privilege of leading an extraordinary staff of professionals and a network of volunteers across our entire country.

We are making dramatic progress that is the result of the scientific excellence of our funded researchers and our volunteer scientific leadership as well as the rapid advancement of available technology. It is now not "if" we will cure IBD, but "when."

Mr. Chairman, I will focus the remainder of my testimony on our appropriations recommendations for fiscal year 2011.

RECOMMENDATIONS FOR FISCAL YEAR 2011

1) CENTERS FOR DISEASE CONTROL AND PREVENTION

INFLAMMATORY BOWEL DISEASE EPIDEMIOLOGY PROGRAM

As I mentioned earlier, CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not have an exact number due to these diseases' complexity and the difficulty in identifying them. Mr. Chairman, we are extremely grateful for your leadership in providing funding over the past five years for an epidemiology program focused on IBD at the Centers for Disease Control and Prevention. This program is the only one of its kind in our long fight against IBD and its accomplishments have been applauded by the

CDC. Unfortunately, the President's FY11 budget proposal recommends that this highly successful program be eliminated. CCFA strongly disagrees with the administration's position and urges the subcommittee to provide full funding for this important research in FY11.

CCFA has been a proud partner with CDC in conducting the research funded under the epidemiology program. For the first two years of the project the Foundation worked collaboratively with Kaiser Permanente in California to better understand the incidence and prevalence of IBD, the natural history of the disease, and why patients respond differently to the same therapy. This research has resulted in 11 publications to date and another 11 papers to be submitted to high-quality peer-reviewed journals. Topics include but are not limited to the following:

- Incidence and Prevalence of IBD
- Patterns of Care and Outcomes in IBD
- Qualitative study of provider opinions
- Utilization of biologics (infliximab)
- Disparities in Mortality
- Myelosuppression during Thiopurine Therapy for Inflammatory Bowel Disease: Implications for Monitoring Recommendations
- Severity and Flare Algorithms
- Disparities in Surveillance for Colorectal Cancer
- Pediatric Epidemiology

In 2007, our focus shifted to the establishment of the "Ocean State Crohn's & Colitis Area Registry" or OSCCAR. Under the leadership of Bruce Sands, MD, this study is being conducted jointly by investigators at the Massachusetts General Hospital and Rhode Island Hospital/Brown University. The state of Rhode Island is an excellent location to conduct a population-based IBD study because; 1) it is a small state geographically; 2) it has a diverse ethnic and socioeconomic population that does not tend to migrate out of state; and 3) a small number of gastroenterologists treat essentially all IBD patients within the state. Since 2007, Dr. Sands has been able to recruit virtually all GI physicians in Rhode Island to refer patients into the study. To date, almost 200 patients have been recruited. All of this progress will be lost if the program is eliminated in 2011.

The goals of the OSCCAR study moving forward are to: 1) describe the age and sex adjusted incidence rate of Crohn's disease and ulcerative colitis; 2) describe variations in presenting symptoms among children, men and women with newly diagnosed disease; 3) identify factors that predict resistance to steroids, including clinical characteristics and blood test markers that could be useful to treating physicians; 4) identify predictors of the need for surgery; and 5) describe factors that predict either impaired quality of life or a benign course of disease

Mr. Chairman, to ensure that this important epidemiological work moves forward in FY11, CCFA recommends an appropriation of \$686,000 (level funded from FY10).

PEDIATRIC INFLAMMATORY BOWEL DISEASE PATIENT REGISTRY

Mr. Chairman, the unique challenges faced by children and adolescents battling IBD are of particular concern to CCFA. In recent years we have seen an increased prevalence of IBD among

children, particularly those diagnosed at a very early age. To combat this alarming trend CCFA, in partnership with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, has instituted an aggressive pediatric research campaign focused on the following areas:

- Growth/Bone Development - How does inflammation cause growth failure and bone disease in children with IBD?
- Genetics – How can we identify early onset Crohn's disease and ulcerative colitis?
- Quality Improvement - Given the wide variation in care provided to children with IBD, how can we standardize treatment and improve patients' growth and well-being?
- Immune Response - What alterations in the childhood immune system put young people at risk for IBD, how does the immune system change with treatment for IBD?
- Psychosocial Functioning – How does diagnosis and treatment for IBD impact depression and anxiety among young people? What approaches work best to improve mood, coping, family function, and quality of life.

The establishment of a national registry of pediatric IBD patients is central to our ability to answer these important research questions. Empowering investigators with HIPPA compliant information on young patients from across the nation will jump-start our effort to expand epidemiologic, basic and clinical research on our pediatric population. We encourage the Subcommittee to support our efforts to establish a Pediatric IBD Patient Registry with the CDC in FY11.

2) NATIONAL INSTITUTES OF HEALTH

Throughout its 40 year history, CCFA has forged remarkably successful research partnerships with the NIH, particularly the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which sponsors the majority of IBD research, and the National Institute of Allergy and Infectious Diseases (NIAID). CCFA provides crucial "seed-funding" to researchers, helping investigators gather preliminary findings, which in turn enables them to pursue advanced IBD research projects through the NIH. This approach led to the identification of the first gene associated with Crohn's -- a landmark breakthrough in understanding this disease.

Mr. Chairman, NIDDK-sponsored research on IBD has been a remarkable success story. In 2008, a consortium of researchers from the United States, Canada, and Europe identified 21 new genes for Crohn's disease. This discovery, funded in part by the NIDDK, brings the total number of known genes associated with Crohn's disease to more than 30 and provides new avenues for the development of promising treatments. We are grateful for the leadership of Dr. Stephen James, Director of NIDDK's Division of Digestive Diseases and Nutrition, for aggressively pursuing this and other promising areas of research.

CCFA's scientific leaders, with significant involvement from NIDDK, have developed an ambitious research agenda entitled "*Challenges in Inflammatory Bowel Diseases.*" In addition,

CCFA-affiliated investigators played a leading role in developing the recommendations on IBD in the new NIH National Commission on Digestive Diseases strategic plan. We look forward to working with the NIDDK to advance the cutting-edge science called for in these two roadmaps.

Mr. Chairman, I also wanted to thank you and your colleagues for the unprecedented support you provided to the NIH as part of the American Recovery and Reinvestment Act. IBD research has benefitted substantially from that investment with more than 15 IBD-specific projects receiving ARRA funding. This portfolio includes grants focused on; pediatric IBD, clinical diagnostics, basic research on the mechanisms of chronic inflammation and the role of the intestinal barrier in IBD, genetics, and new therapeutic approaches. This research has the potential to dramatically improve the quality of life for our patients and we thank you for making this possible.

For FY11, CCFA joins with other voluntary patient and medical organizations in recommending an appropriation of \$35 billion for the NIH.

Once again Mr. Chairman, thank you very much for the opportunity to submit our views for your consideration.



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 President and Chief Executive Officer
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On behalf of the Cystic Fibrosis Foundation and the 30,000 people with cystic fibrosis (CF), we are pleased to submit the following testimony regarding fiscal year 2010 appropriations for cystic fibrosis-related research at the National Institutes of Health (NIH) and other agencies.

ABOUT CYSTIC FIBROSIS

Cystic fibrosis is a life-threatening genetic disease for which there is no cure. People with CF have two copies of a defective gene, known as CFTR, which causes the body to produce abnormally thick, sticky mucus that clogs the lungs and results in fatal lung infections. The thick mucus in those with CF also obstructs the pancreas, making it difficult for patients to absorb nutrients from food.

Since its founding, the Cystic Fibrosis Foundation has maintained its focus on promoting research and improving treatments for CF. More than thirty drugs are now in development to treat CF; some treat the basic defect of the disease, while others target its symptoms. Through the research leadership of the Cystic Fibrosis Foundation, the life expectancy of individuals with CF has been boosted from less than 6 years in 1955 to 37 years today. This improvement in the life expectancy for those with CF can be attributed to research advances and to the teams of CF caregivers who offer specialized care. Although life expectancy has improved dramatically, we continue to lose young lives to this disease.

The promise for people with CF lies in research. In the past five years, the Cystic Fibrosis Foundation has invested over \$660 million in its medical programs of drug discovery, drug development, research, and care focused on life-sustaining treatments and a cure for CF. A greater investment is necessary, however, to accelerate the pace of discovery and development of CF therapies. This testimony focuses on the investment required to rapidly and efficiently discover and develop new CF treatments aimed at controlling and curing CF.

SUSTAINING THE FEDERAL INVESTMENT IN BIOMEDICAL RESEARCH

This Subcommittee and Congress are to be commended for their steadfast support for biomedical research and their commitment to the National Institutes of Health (NIH), particularly the effort to double the NIH budget between FY 1999 and FY 2003 as well as the significant investment provided by the American Recovery and Reinvestment Act (ARRA) in 2009. These increases in funding brought a new era in drug discovery that has benefited all Americans. Congress must adequately fund the NIH so that it can capitalize on scientific advances in order to maintain the momentum generated by the doubling of funds and the infusion from ARRA.

The flat-funding of the NIH since 2003 has decreased purchasing power, limiting the pursuit of

critical research. The Cystic Fibrosis Foundation joins the Coalition for Health Funding to recommend all health discretionary spending be increased \$67.1 billion in FY 2011, or \$9.3 billion over the FY 2010 levels. This increased investment will help maintain the NIH's ability to fund essential biomedical research today that will provide the care and cures of tomorrow. If the Committee is not able to recommend funding at this level, Congress should advise the NIH to focus on contributing funds to research partnerships that will accelerate therapeutic development to improve people's lives.

STRENGTHENING CLINICAL RESEARCH AND DRUG DEVELOPMENT

The Cystic Fibrosis Foundation has been recognized for its unique research approach which encompasses everything from basic research through Phase III clinical trials, and has created the infrastructure required to accelerate the development of new CF therapies. As a result, we now have a pipeline of more than thirty potential therapies which are being examined to treat people with CF. As a prime example, in February 2010, Cayston® a new much-needed antibiotic that combats recurrent lung infections, arrived in the hands of people with CF. This new treatment is a direct result of the Foundation's innovative research agenda, advancing from bench to bedside through the Foundation's research program which speeds the creation of new CF therapies. Our successes, and specifically our Therapeutics Development Network discussed below, can serve as a map for the development of new treatments for other diseases.

The Foundation is a leader in creating a clinical trials network to achieve greater efficiency in clinical investigation. Because the CF population is small, a higher proportion of people with the disease must partake in clinical trials than in most other diseases. This unique challenge prompted the Foundation to streamline our clinical trials processes. As a result, research conducted by the Foundation is more efficient than ever before and we are a model for other disease groups.

We applaud the efforts by the nation's health agencies to encourage greater efficiency in clinical research and we are hopeful that the Committee will direct the national health agencies to pay special attention to advances in treatment methods and mechanisms for translating basic research across institutes into therapies that can benefit patients.

Development of Rare Disease Research Networks

The Committee should direct the NIH and other agencies to allocate additional funds for innovative therapeutics development models including the Therapeutics for Rare and Neglected Diseases (TRND) and Cures Acceleration Network (CAN) programs as well as for clinical research to meet the demand for testing promising new therapies for cystic fibrosis and other diseases. Support should also be directed toward the continuation of other rare disease research networks, such as the NIH's pediatric liver disease consortium.

The CF Foundation's established clinical research program, the Therapeutics Development Network (TDN), plays a pivotal role in accelerating the development of new treatments to improve the length and quality of life for cystic fibrosis patients. Lessons learned from the TDN's centralization of data management and analysis and data safety monitoring in the TDN will be useful in designing clinical trial networks for other diseases. Dr. Francis Collins, director of the NIH, has specifically cited the TDN as an exemplar for TRND. Coupled with the newly established CAN, the time between discovery and development of drugs and therapies can be accelerated if these programs are fully funded.

Providing for the U.S. Food and Drug Administration (FDA)

We urge the Committee to increase funding for the FDA to ensure that the Agency has the necessary resources and funding to effectively evaluate new and emerging treatments. In order to be effective, the FDA needs not only an adequate number of reviewers of new treatments, but also those with the appropriate skills and expertise, particularly for rare diseases like cystic fibrosis. Additional support for the FDA through increased funding not only assures that the nation has a safe and effective supply of drugs and devices, but also that the agency can give the necessary attention to reviewing treatments that treat small populations but serve specific unmet medical needs, such as Cayston®.

The CF Foundation applauds the appointment of Dr. Anne Pariser as the new Associate Director for Rare Diseases in the FDA's Center for Drug Evaluation and Research's Office of New Drugs. We are pleased to see this new position held by such a capable and competent administrator. Similarly, we applaud the regulatory science initiative formed by the NIH and the FDA with the goal of accelerating the development and use of new approaches to evaluate drug safety, efficacy and quality and urge the Committee to strongly support this type of collaboration. Support for coordination between new programs like TRND and CAN throughout the national health agencies leverages the federal investment in new research, facilitating swifter development and delivery of new medical treatments.

Supporting Translational Research and Investigators

A significant discrepancy persists between the first award funding granted to clinical laboratory investigators and that granted to basic laboratory investigators. The difference is even greater for second awards and prolonged funding of clinical investigators. The NIH must maintain support for translational research and the investigators piloting those projects. Without this support, the NIH stands to lose an entire generation of clinically trained individuals committed to clinical research. The "generation gap" that would be created by the loss of these clinical researchers would affect the ability of the NIH to conduct world-class clinical investigation and jeopardize the standing of the United States as the world's premiere source for biomedical research.

The Clinical and Translational Science Awards (CTSA)

We urge the NIH to enhance the Clinical and Translational Science Awards (CTSA), a program designed to transform the way in which clinical and translational research is conducted. Such an increased emphasis on clinical translation can enable researchers to provide new treatments more efficiently to patients. For example, at Seattle Children's Hospital, a CTSA program has been instrumental in identifying best practices for efficient clinical trial participation and improving clinical outcomes in care for cystic fibrosis. Tremendous effort has brought institutions together to rally around this program and similar programs at other institutions, yet current funding levels make it difficult for the full complement of programs to be funded. Additionally, key to the success of the CTSA is the development of cost-sharing for use of infrastructure services. An example of this mechanism is the General Clinical Research Centers (GCRC), which allowed institutes to reduce their research budgets by having investigators use the GCRC when clinical care was made available at no additional cost. In order to maximize the potential of the CTSA, multiple institutes within the NIH must be able to provide financial resources for critical programs such as this.

Alternative Models for Institutional Review Boards (IRB)

We are pleased that the Department of Health and Human Services has encouraged the exploration of alternative models of IRBs, including central IRBs, by the CTSA. We encourage Congress to urge the Department to demonstrate more aggressive leadership in persuading all academic institutions to accept review by a central IRB—without insisting on parallel and often duplicative review by their own IRB—at least in the case of multi-institutional trials in rare diseases. Such oversight could help provide greater expertise to improve trial design and enable critical research to move forward in a timelier manner without undermining patient safety.

Research Compensation for Supplemental Security Income

An additional impediment in our effort to accelerate the development of new therapies is the Social Security Administration's current Supplemental Security Income (SSI) rules, which count research compensation for participation in a clinical drug study as income for determining SSI. This policy creates an unnecessary barrier to clinical trial participation for a significant number of people with CF, and thus severely limits efforts to develop new therapies. H.R. 2866, the Improving Access to Clinical Trials Act of 2009, would allow the Social Security Administration to disregard any income received from compensation for clinical trials when determining eligibility for programs like SSI. Support from the Committee on resolving this disincentive toward clinical research is appreciated.

Partnership with the National Center for Research Resources (NCRR)

The CTSA program, administered by the NCRR, encourages novel approaches to clinical and translational research, enhances the utilization of informatics, and strengthens the training of young investigators. The Cystic Fibrosis Foundation has enjoyed a productive relationship with the NCRR to support our vision for improving clinical trials capacity through its early financial support of the TDN. Recently, however, the NCRR decided to reject funding for disease-specific networks in favor of those without a disease focus. As a result of this policy, some of the best clinical research consortia are prohibited from competing for NCRR grants, including but not limited to the CF TDN. We urge the NCRR to reverse this decision.

SUPPORTING DRUG DISCOVERY

The Cystic Fibrosis Foundation's clinical research is fueled by a vigorous drug discovery effort—early stage translational research of promising strategies to find successful treatments for this disease. Several research projects at the NIH will expand our knowledge about the disease, and could eventually be the key for controlling or curing cystic fibrosis.

Opportunities in Animal Models

The Cystic Fibrosis Foundation is encouraged by the NIH's investment in a research program at the University of Iowa to study the effects of CF in a pig model. The program, funded through research awards from both NHLBI and the Cystic Fibrosis Foundation, bears great promise to help make significant developments in the search for a cure. While a company has been established to produce the animals, the infrastructure and extensive animal husbandry required to keep the animals alive and conduct research on them is available at few academic institutions. We urge additional funding to create a facility that would enable researchers from multiple institutions to conduct research with these models.

Facilitating Scientific Data Connections

An explosion of data is emerging from “big science” projects such as the Human Genome Project and the International HapMap Project. We encourage investments by NIH into the development of systems that permit the linkage of gene expression, protein expression and protein interaction data from independent laboratories. While construction of such an interface would be difficult, it would undoubtedly facilitate generations of new ideas and open new areas of medically important biology.

Increasing Investment in Inflammatory Response Research

Cystic fibrosis, like diseases such as inflammatory bowel disease, chronic bronchitis, and rheumatoid arthritis, causes an intense inflammatory response. The Cystic Fibrosis Foundation enthusiastically supports investments by the NIH to gain a greater understanding of neutrophil-driven inflammatory responses, which would lead to improved methods of safely interfering with the inflammatory process and contributing to the health and wellbeing of the US population.

Supporting High Throughput Screening

The committee should urge the NIH to continue to fund high throughput screening initiatives in keeping with Common Fund priorities. Support for the follow-up and optimization of compounds identified through this type of screening can help to bridge the development gap and bring about more drugs that can make it to patients’ bedsides.

Funding Systems Biology Platforms

In order to rapidly accelerate the identification of potential biomarkers and understand the mechanisms of action of CFTR function, data generated from multiple laboratories and scientific centers must be integrated. To address this, the Cystic Fibrosis Foundation has partnered with a systems biology company called GeneGo to generate a cystic fibrosis-focused systems biology platform to illustrate the various effects of CFTR dysfunction in multiple cell systems. The CF Foundation urges NIH to provide additional funding to support research efforts aimed at leveraging systems biology platforms to integrate multiple disciplines within the CF research community in order to accelerate drug development and biomarker validation for cystic fibrosis.

Small Business Innovation Research Program at NIH

Small Business Innovation Research (SBIR) program grants allocated by the NIH have helped many small biotechnology and pharmaceutical companies to develop vital treatments for a variety of diseases. The SBIR program could provide further support by directing that a portion of all grants awarded be used for rare disease research. With such a small portion of the population likely to purchase the drugs, research to produce drugs to treat rare diseases is often considered too large a financial risk to take on. It is important to note, however that there are over 25 million Americans with a rare disease. By directing even small dollar grants to develop drugs for these diseases, Congress can eliminate some of the risk that keeps biotechnology and pharmaceutical companies from developing drugs for rare diseases.

The NIH has wisely focused on translational research as a touchstone for ensuring the relevance of the agency to the American public. The CF Foundation is the perfect example of this notion, having devoted our own resources to developing treatments through drug discovery, clinical development, and clinical care. Several of the drugs in our pipeline show remarkable promise in clinical trials and we are increasingly hopeful that these discoveries will bring us even closer to a cure. Encouraged by our successes, we believe the experience of the CF Foundation in clinical

research can serve as a model of drug discovery and development for research on other orphan diseases and we stand ready to work with NIH and Congressional leaders. On behalf of the Cystic Fibrosis Foundation, we thank the Committee for its consideration.

Terri Eldridge

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Public Witness Testimony

Dandy-Walker Syndrome

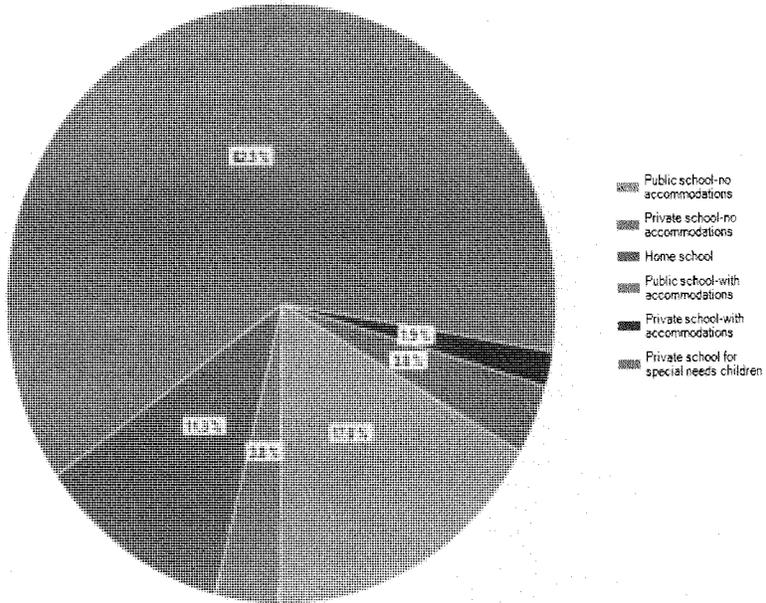
Dandy-Walker Syndrome is the most common congenital hind brain malformation, affecting as many as 1 in 5000 live births. It typically consists of an underdeveloped or completely absent cerebral vermis (the area that connects the two hemispheres of the cerebellum), dilation of the 4th ventricle (one of the fluid filled spaces within the brain) and a cystic formation near the internal base of the skull. Dandy Walker patients often have secondary conditions that may consist of hydrocephalus (up to 70%), seizure disorders (30%), and heart, facial or limb malformations as well as other central nervous system abnormalities.

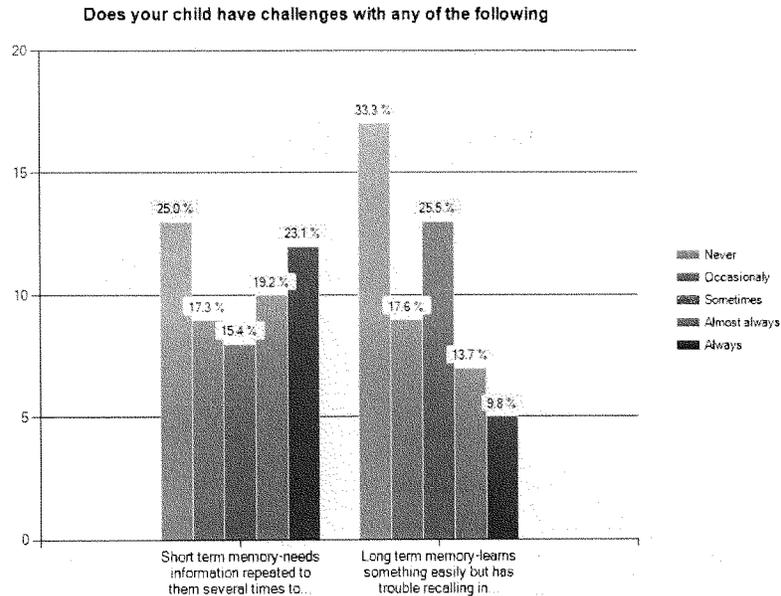
Almost every day in our country a baby is born with Dandy-Walker Syndrome. I come here today not only as the Grandmother of one of these children but also as a volunteer who communicates everyday with families all over the country affected by Dandy-Walker Syndrome. I hear their stories, their frustration, their fear and heartbreak. Many of them have created their own online community where they support each other and share information that the medical community is unable to provide to them. They are frustrated by the lack of information from their physicians. Imagine your child being diagnosed with a potentially disabling condition and the doctor's best answer is "I don't know". I often get calls from families looking for a physician in their area who is an "expert" in Dandy-Walker Syndrome and have to tell them that one doesn't exist, only adding to their anguish. Most families are given worst case scenarios when they or a loved one is diagnosed and then are even more frustrated when they connect with other families and find out that there are many children out there that, although have challenges, aren't near as bad off as they were lead to believe. It is difficult for them to understand that doctors are only able to share with them what they read in medical journals and because research is so scarce, especially in the area of outcomes that the information just doesn't exist for them to give. Connecting with other families and learning about their first hand experience with a person with Dandy-Walker Syndrome has helped many families. But what about the families out there that do not have the resources to make these kinds of connections or do not have access to the Internet? They are left to rely on the information provided to them through the medical community that is often based on outdated worst case scenario research. How many families have terminated a pregnancy on their doctor's advice only to later find a community of thriving individuals with Dandy-Walker

Syndrome? I can tell you that the number is staggering because I speak with these families everyday when they call looking for answers and support. I can't think of a greater injustice; the heartbreak these families must face is unthinkable.

The outcomes for people diagnosed with Dandy-Walker Syndrome vary drastically, and the severity of the malformation doesn't always correlate with the severity of the outcome. This lack of outcome tracking is just one of the many areas we need additional research in to so families can be provided with accurate expectations after a diagnosis. It is also crucial to establish disease burden estimates that don't exist today, which could play a role in increased scientific interest and research funding. The following two charts illustrate the broad range of opportunities, challenges and services many families experience after receiving a Dandy-Walker Syndrome diagnosis.

Does your child attend





As you can see, the range of disability related to Dandy-Walker Syndrome is all over the board. We need to find out why and in the process educate clinicians so that the advice they give families is not just the worst case scenario which rarely is the outcome.

I come to you today to respectfully ask that you help all current and future families who are or who will be affected by a Dandy-Walker Syndrome diagnosis by asking the NIH to establish a research plan for Dandy-Walker Syndrome. This plan should outline the various types of research needed in relation to Dandy-Walker Syndrome and should include genetic research, basic science, translational science and research for better treatments. The NIH would then be able to set better priorities in funding for those projects that facilitate the forward progress of such a plan.

I also respectfully request that the Center for Disease Control use their resources to compile an epidemiology study that would provide the medical community, researchers and families of affected individuals with accurate data in the area of disease burden and track the long term outcomes of individuals given the Dandy-Walker Syndrome diagnosis. Currently there is very little epidemiology information for Dandy Walker Syndrome. This information is crucial in finding not only a cure but better treatments for Dandy Walker Syndrome. The research community needs solid data regarding the number of affected individuals as well as the number of pregnancies that result in a Dandy-Walker Syndrome diagnosis. Today the suggested rate of occurrence range is anywhere from 1 in 5000 live births to 1 in 35000 live births. There are some doctors in the research community who believe even the 1 in 5000 is a underestimate of the true rate of prevalence. These already varying numbers and the "live birth" caveat do not take into account miscarriages, terminated pregnancies or adults diagnosed later in life. When you factor in these cases of Dandy-Walker Syndrome the incident rate will grow; perhaps substantially.

The final way Congress can help individuals affected by Dandy-Walker Syndrome is by ensuring the goals and priorities set forth in the 110th Congress House Concurrent Resolution 163 continue to be a focus for the NIH and the Center for Disease Control and ask what progress has been made since the legislation's passage. HCR163 expressed the sense of Congress that the Director of the National Institutes of Health should continue the current collaboration, with respect to Dandy-Walker syndrome, among the National Human Genome Research Institute, the National Institute of Biomedical Imaging and Bioengineering, the National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, and the Office of Rare Diseases; further research into the epidemiology, diagnosis, pathophysiology, disease burden, and improved treatment of Dandy-Walker syndrome and hydrocephalus should be conducted and supported; and that public awareness and professional education regarding Dandy-Walker research should increase through partnerships between the Federal Government and patient advocacy organizations, such as the Dandy-Walker Alliance and the Hydrocephalus Association. Passing a non-binding resolution was the first step. Now I, my granddaughter and all American's living with Dandy-Walker Syndrome need your help ensuring that the NIH and CDC are working to accomplish these goals.

Dennis L. Kochniuk, MS Safety and Health, CSP, CHS, DABFE
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April 15, 2010

I have been a safety professional for over 40 years. My initial safety training was in the U.S. Navy submarine service where I realized just how important a safe operation is. I have served in safety functions from an inspector to a corporate safety manager to a consultant for industry and government. I have worked with both VPP and non-VPP sites, both union and non-union, from Mom and Pop businesses to billion dollar international corporations (US owned).

My personal experience has been right in line with what the statistics show. The OSHA consultation services and in particular the VPP Program has been a much more successful return on investment in time and money for worker safety than the enforcement program. Retreating from an aggressive VPP Program to increase enforcement will not, in my opinion, improve worker safety; it will decrease it by returning to an "us versus them" mentality which hurts the safety of the worker.

There is a reason the VPP sites have a better safety record than industry in general and that is because the VPP program encourages everyone to care about and work toward the well being and safety of their fellow employee.

Unfortunately, enforcement is required because not everyone has the conviction that a safe business is a more successful business; but taking away from a proven program (VPP) to enhance enforcement will not, in my experience, improve the situation or make the overall workplace safer, it will detract from it.

For these reasons I ask that funding for VPP not be decreased, but to ensure that a portion of the funding increase for OSHA is used to expand and improve this proven program.

Sincerely,

Dennis L. Kochniuk

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**STATEMENT OF
JANET HIESHETTER
EXECUTIVE DIRECTOR
DYSTONIA MEDICAL RESEARCH FOUNDATION**

**ON BEHALF OF THE
DYSTONIA MEDICAL RESEARCH FOUNDATION
ONE EAST WACKER DRIVE, SUITE 2810
CHICAGO, IL 60601**

**REGARDING FISCAL YEAR 2011 APPROPRIATIONS FOR THE
NATIONAL INSTITUTES OF HEALTH AND THE
NATIONAL INSTITUTE OF
NEUROLOGICAL DISORDERS AND STROKE**

**SUBMITTED TO THE
HOUSE COMMITTEE ON APPROPRIATIONS; SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND
RELATED AGENCIES**

APRIL 16, 2010

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2011:

- **PROVIDE A 12% FUNDING INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND CONCURRENT INCREASES ACROSS ITS INSTITUTES AND CENTERS.**
- **EXPAND DYSTONIA RESEARCH AT THE NIH THROUGH THE NATIONAL INSTITUTE ON NEUROLOGICAL DISORDERS AND STROKE (NINDS), THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD), THE NATIONAL EYE INSTITUTE (NEI), AND THE NATIONAL INSTITUTE ON CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD).**
- **CONTINUE TO ADVANCE DYSTONIA RESEARCH THROUGH PARTNERSHIPS WITH THE OFFICE OF RARE DISEASE**

RESEARCH (ORDR) AND THE RARE DISEASES CLINICAL RESEARCH NETWORK (RDCRN).

- **PROVIDE SUPPORT FOR THE CURES ACCELERATION NETWORK (CAN) AT A LEVEL OF \$500 MILLION, AS AUTHORIZED IN HEALTHCARE REFORM LEGISLATION.**

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Dystonia can affect movement in several different ways; focal dystonia affect specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed and proved particularly useful to control patients' symptoms. Botulinum toxin (Botox/Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. More research is needed to fully understand the onset and progression of the disease, in order to better treat patients. Until a cure is discovered, the development of management therapies remains vital.

DEEP BRAIN STIMULATIONS (DBS)

Deep brain stimulation (DBS) is a surgical procedure originally developed to treat Parkinson's disease, but is now being applied to severe cases of dystonia. A neurostimulator, or "brain pacemaker" is surgically implanted to deliver electrical stimulation to the areas that control movement. While the exact reasons for effectiveness are unknown, the electrical stimulation blocks abnormal nerve signals that cause debilitating muscle spasms and contractions.

DBS was approved for use by dystonia patients in 2003 and has since drastically improved the lives of many individuals. Results have ranged from quickly regaining the ability to walk and speak, to regaining complete control over one's body and returning to an independent life as an able-bodied person. DBS is currently used to treat severe cases of generalized dystonia, but with increased research may also be a promising treatment for those suffering from focal dystonias. Surgical interventions are a crucial and active area of dystonia research, and must be pursued in the development of new treatment options.

BOTULINUM TOXIN INJECTIONS (BOTOX/MYOBLOC)

The introduction of botulinum toxin as a therapeutic tool in the late 1980s revolutionized the treatment of dystonia by offering a new, localized method to significantly relieve symptoms for many people. Botulinum toxin, a biological product, is injected into specific muscles where it

acts to relax the muscles and reduce excessive muscle contractions.

Botulinum toxin is derived from the bacterium *Clostridium botulinum*. It is a nerve "blocker" that binds to the nerves that lead to the muscle and prevents the release of acetylcholine, a neurotransmitter that activates muscle contractions. If the message is blocked, muscle spasms are significantly reduced or eliminated, providing considerable relief from the patient's symptoms.

Injections of botulinum toxin should only be performed by a physician who is trained to administer this treatment. The physician administering treatment may palpate the muscles carefully, trying to ascertain which muscles are over-contracting and which muscles may be compensating. In some instances, such as in the treatment of laryngeal dystonia, a team approach including other specialists may be required.

For selected areas of the body, and particularly when injecting muscles that are difficult or impossible to palpate, guidance using an electromyograph (EMG) may be necessary. For instance, when injecting the deep muscles of the jaw, neck, or vocal cords, an EMG-guided injection may improve precision since these muscles cannot be readily palpated. An EMG measures and records muscle activity and may help the physician locate overactive muscles.

Injections into the overactive muscle are done with a small needle, with one to three injections per muscle. Discomfort at the site of injections is usually temporary, and a local anesthetic is sometimes used to minimize any discomfort associated with the injection. Many dystonia patients frequently rely on botulinum toxins injections to maintain their improved standard of living due to the fact that the benefits of the treatment peak in approximately four weeks and lasts just three or four months. Currently, FDA approved forms of botulinum toxin include Botox and Myobloc.

DMRF supports the recent "follow-on" biologics or biosimilars provisions included in the *Patient Protection and Affordable Care Act*. This creates a regulatory pathway for biosimilars at the Food and Drug Administration (FDA). This will help remove significant cost barriers to treatment for dystonia patients and maintain strong patient protections, while providing incentive for the development of new biologic treatments.

DYSTONIA AND THE NATIONAL INSTITUTES OF HEALTH (NIH)

Currently, dystonia research at NIH is conducted through the National Institutes on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the Office of the Director.

NATIONAL INSTITUTE ON NEUROLOGICAL DISORDERS AND STROKE (NINDS)

The majority of dystonia research at NIH is conducted through NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research included gene discovery, the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and

cellular studies inherited forms of dystonia, epidemiology studies, and brain imaging. DMRF works to support NINDS in conducting critical research and advancing understating of dystonia.

NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD)

NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia. Spasmodic dysphonia is a form of focal dystonia, and involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. Our understanding of spasmodic dysphonia has been greatly enhanced by research initiatives at NIDCD, like the brainstem systems studies. DMRF encourages partnerships between NINDS and NIDCD to further dystonia research.

NATIONAL EYE INSTITUTE (NEI)

NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids from an unknown cause that is associated with abnormal function of the basal ganglion. The condition can progress to the point where facial spasms develop. While myectomy surgery, botulinum toxin injections, and oral medication can help manage some of the symptoms of blepharospasm, further study by NEI is needed to develop more predictable treatment options.

Rare Diseases Clinical Research Network (RDCRN)

The second phase of the RDCRN at NIH provided funding for an additional 19 grants aimed at studying the natural history, epidemiology, diagnosis, and treatment of rare diseases. This includes the Dystonia Coalition, which will facilitate collaboration between researchers, patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial dystonia, and limb dystonia. Working primarily through NINDS and the Office of Rare Disease Research in the Office of the Director, the RDCRN holds great hope for advancing understanding and treatment of primary focal dystonias.

After years of near-level funding for NIH, the \$10.4 billion provided in the American Recovery and Reinvestment Act (ARRA) helped reinvigorate biomedical research efforts. However, as those funds come to an end, DMRF joins the greater biomedical research community in its concern that research funding will “fall off the cliff.” In order to prevent the loss of research spearheaded under ARRA, continued support for initiatives like the Cures Acceleration Network (CAN) included in the recent healthcare reform legislation are vital as we push for rapid translation of basic science into clinical treatments.

For FY 2011, DMRF recommends a funding increase of at least 12% for NIH and its Institutes and Centers.

For FY 2011, DMRF recommends that the NIH expand dystonia research through the National Institute on Neurological Disorders and Stroke, the National Institute on Deafness and Other

Communication Disorders, the National Eye Institute, and the National Institute on Child Health and Human Development.

For FY 2011, DMRF recommends continued partnerships on dystonia research between the Office of Rare Disease Research, the Rare Diseases Clinical Research Network, and the dystonia patient community.

For FY 2011, DMRF recommends appropriating \$500 million for the Cures Acceleration Network, as authorized in the Patient Protection and Affordable Care Act.

THE DYSTONIA MEDICAL RESEARCH FOUNDATION (DMRF)

The Dystonia Medical Research Foundation was founded over 30 years ago and has been a membership-driven organization since 1993. Since our inception, the goals of DMRF have remained: to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.



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**FY 2011 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY
SUBMITTED BY THE ENDOCRINE SOCIETY
FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES
DIRECTED AT THE DEPARTMENT OF HEALTH AND HUMAN
SERVICES/NATIONAL INSTITUTES OF HEALTH**

The Endocrine Society is pleased to submit the following testimony regarding Fiscal Year 2011 federal appropriations for biomedical research, with an emphasis on appropriations for the National Institutes of Health (NIH). The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 14,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of researchers who depend on federal support for their careers and their scientific advances.

Each year, the NIH funds thousands of research grants, facilitating the discovery of methods of prevention, treatment, and cure for debilitating diseases that negatively impact the health of the nation's citizens and fuel rising health care costs. Nearly half of all Americans have a chronic medical condition, and these diseases now cause more than half of all deaths worldwide. Deaths attributed to chronic conditions could reach 36 million by 2015 if the trend continues unabated.

Congress and President Obama recognized the contributions of NIH to the health of the nation and the nation's economy by awarding the agency more than \$10 billion through the American Recovery and Reinvestment Act. These funds supported more than 12,000 grants and created more than 50,000 jobs. ARRA funds have allowed the NIH to award grants, including those described in the bulleted list below, which will lead to breakthroughs in hundreds of disease areas, including those chronic diseases that result in the death of so many people each year.

- A project is using information from a clinical trial in people with type 2 diabetes and heart disease to examine the association between fat cell hormones and CVD, including their potential usefulness in prognosis, monitoring effects of therapy, and identifying risk
- A project will conduct research in mice to develop a vehicle to deliver a specific gene that may prevent type 1 diabetes
- A grant to provide insights into the mechanisms by which diet and exercise reduce abdominal fatness and improve cardiovascular health in overweight and obese persons with type 2 diabetes. These mechanisms include systemic inflammation, insulin sensitivity, and aerobic and strength fitness

- Researchers will define how certain carbohydrate molecules affect hormone function, to better understand reproductive development, and development of breast and prostate cancer
- Scientists will assess how a specific gene helps trigger the development of stem cells into sperm, which could lead to new treatments for male infertility or new contraceptive targets
- A project will investigate the role of developmental exposure to Bisphenol A (BPA) on obesity and metabolic syndrome.

Most of these grants would not have been funded through the regular grant approval process, and without the ARRA funds, the discoveries that are expected to result from these projects would never have a chance to be made. Furthermore, many of the scientists funded through these grants may never have received the funds necessary to start or continue their careers, including many first-time awardees. As the United States continues to lose its place as the world leader in innovation, we cannot miss out on opportunities to award bright young scientists and engage them in the research process.

Unfortunately, the grants and jobs created will disappear at the end of FY 2010 if Congress does not sustain the momentum created by the ARRA funds with a significant increase in the FY 2011 budget. While it is not feasible to expect that the NIH budget can be increased in one year to a level that will sustain the 12,000 grants awarded through the ARRA funds, Congress must do what it can to ensure that NIH receives steady, sustainable, predictable increases that avoid the boom and bust cycle that NIH experienced with the doubling of its budget, and now faces again with the end of the ARRA funds.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the federal government. The Society strongly supports the continued increase in federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address the burgeoning scientific opportunities and new health challenges that continue to confront us. The Endocrine Society recommends that NIH receive \$37 billion in FY 2011 to prepare for the post-stimulus era and ensure the steady and sustainable growth necessary to continue building on the advances made by scientists during the past decade.

**Testimony of Daniel Paul Perez, President & CEO, FSH Society, Inc.
 Telephone: (781) 275-7781, e-mail: daniel.perez@fshsociety.org before the Subcommittee
 on Labor, Health and Human Services, Education and Related Agencies on the Subject of
 FY2011 Appropriations for National Institutes of Health (NIH)
 Research on FSHD (Facioscapulohumeral Muscular Dystrophy) -- April 16, 2010**

Mr. Chairman, it is a great pleasure to submit this testimony to you today.

My name is Daniel Paul Perez, of Bedford, Massachusetts, and I am testifying today as President & CEO of the FSH Society, Inc. (facioscapulohumeral muscular dystrophy) and as an individual who has this common and most prevalent form of muscular dystrophy. My testimony is about the profound and devastating effects of a disease known as facioscapulohumeral muscular dystrophy which is also known as facioscapulohumeral muscular disease, FSH muscular dystrophy or FSHD, and the urgent need for increased NIH funding for research on this disorder. For men, women, and children the major consequence of inheriting the most prevalent form of muscular dystrophy, FSHD, is a lifelong progressive and severe loss of all skeletal muscles. FSHD is a terrible, crippling and life shortening disease. No one is immune, it is genetically and spontaneously (by mutation) transmitted to children and it affects entire family constellations.

**Fact1
 FSHD is The Most Prevalent Form of Muscular Dystrophy**

It is a fact that FSHD is published in the scientific literature as the most prevalent muscular dystrophy in the world. The incidence of FSHD is conservatively estimated to be 1 in 14,000. The prevalence of the disease, those living with the disease, ranges to two or three times as many as that number based on our increasing experiences with the disease and more available and accurate genetic diagnostic tests.

The French government research agency, INSERM (Institut National de la Santé et de la Recherche Médicale) is comparable to the U.S. NIH, and it recently published prevalence data for hundreds of diseases in Europe. Notable is the "Orphanet Series" reports covering topics relevant to all rare diseases. The "Prevalence or reported number of published cases listed in alphabetical order of disease" November 2008 - Issue 10 report can be found at internet web site (http://www.orpha.net/orphacom/cahiers/docs/GB/Prevalence_of_rare_diseases_by_alphabetical_list.pdf). This publication contains new epidemiological data and modifications to existing data for which new information has been made available. This new information ranks facioscapulohumeral muscular dystrophy (FSHD) as the most prevalent muscular dystrophy followed by Duchenne (DMD) and Becker Muscular dystrophy (BMD) and then in turn myotonic dystrophy (DM). FSHD is historically presented as the third most prevalent muscular dystrophy in the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 and 2008 (the MD-CARE Act). This new data ranks FSHD as the first and most prevalent form of muscular dystrophy.

Estimated Prevalence (Cases / 100,000)

| | |
|--|-------------|
| Facioscapulohumeral muscular dystrophy (FSHD) | 7 / 100,000 |
| Duchenne (DMD) and Becker Muscular dystrophy (BMD) | 5 / 100,000 |

Steinert myotonic dystrophy (DM)

4.5 / 100,000

Fact 2

NIH Muscular Dystrophy Funding Has Quadrupled Since Inception of the MD CARE Act

Figures from the online RCDC RePORT and the NIH Appropriations History for Muscular Dystrophy report historically provided by NIH/OD Budget Office & NIH OCPL show that from the inception of the MD CARE Act 2001, funding has nearly quadrupled from \$21 million to \$83 million in FY2009 for muscular dystrophy.

Fact 3

NIH Funding of FSHD has Remained Level Since the Inception of the MD CARE Act

In fiscal year 2009, FSHD was 6.02% of the total muscular dystrophy funding (\$5M / \$83M). The previous year FSHD was 5.3% of the total muscular dystrophy funding (\$3M / \$56M). FSHD funding has simply kept its ratio in the NIH funding portfolio and has not grown in the last eight years.

National Institutes of Health (NIH) FSHD Funding & Appropriations

Sources: NIH/OD Budget Office & NIH OCPL & NIH RCDC RePORT

| Fiscal Year | FSHD Research Dollars (in millions) | FSHD % of MD |
|--------------------|--|---------------------|
| 2002 | \$1.3 | 5% |
| 2003 | \$1.5 | 4% |
| 2004 | \$2.2 | 6% |
| 2005 | \$2.0 | 5% |
| 2006 | \$1.7 | 4% |
| 2007 | \$3 | 5% |
| 2008 | \$3 | 5% |
| 2009 | \$5 | 6% |

We highly commend the Director of the NIH on the ease of use and the accuracy of the Research Portfolio Online Reporting Tool (RePORT) report "Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)" with respect to reporting projects on facioscapulohumeral muscular dystrophy.

Fact 4

FSHD: The Most Prevalent Form of Muscular Dystrophy is Drastically Underfunded at NIH

Now, FSHD is published as the most prevalent muscular dystrophy, and given the extraordinary interest of the scientific and clinical communities in its unique disease mechanism, it defies credibility that it still remains the most prevalent and one of the most underfunded dystrophies at the NIH and in the federal research agency system (CDC, DoD and FDA).

In 2009, the most prevalent muscular dystrophy, FSHD, received \$5 million from NIH. In 2009, the second most prevalent dystrophy, Duchenne (DMD) and Becker Muscular dystrophy (BMD) type, received \$33 million from NIH. In 2009, the third most prevalent dystrophy myotonic dystrophy (DM), received \$13 million from NIH.

The MD CARE Act 2008, mandates the NIH Director to intensify efforts and research in the muscular dystrophies, including FSHD, across the entire NIH. It should be very concerning that in the last eight years muscular dystrophy has quadrupled to \$83 million and that FSHD has remained on average at five (5) percent of the NIH muscular dystrophy portfolio. FSHD is certainly still far behind when we look at the breadth of research coverage NIH-wide.

It is now time to examine why FSHD receives such a disproportional and inverse level of funding despite its equal burden of disease and highest prevalence. It is crystal clear, if not completely black and white, that we are not achieving the goals of parity in funding as expected by the mandates set forth in the MD CARE Acts 2001/2008 and by the NIH Action Plan for the Muscular Dystrophies as submitted to the Congress by the NIH.

We would like to commend the program staff at the NIH for the excellent progress made in FSHD and the extraordinary progress made in increasing muscular dystrophy funding. We are very pleased with the efforts of NIH staff and Muscular Dystrophy Coordinating Committee (MDCC) on behalf of the community of patients and their families with muscle disease and the research community pursuing solutions for all of us. We recognize in particular the efforts and hard work of the following NIH staff: **Story Landis, Ph.D.**, Executive Secretary, MDCC and Director, National Institute of Neurological Disorders and Stroke (NINDS); **John D. Porter, Ph.D.**, Executive Secretary, MDCC and Program Director, Neuromuscular Disease, Neurogenetics Cluster and the Technology Development Program, NINDS; **Stephen I. Katz, M.D., Ph.D.**, Director, National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS); **Glen H. Nuckolls, Ph.D.**, Extramural Programs, Musculoskeletal Diseases Branch, NIAMS; **James W. Hanson, M.D.**, Director of the Center for Developmental Biology and Perinatal Medicine, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD); and, **Ljubisa Vitkovic, M.D., Ph.D.**, Mental Retardation and Developmental Disabilities Branch, DHHS NIH NICHD.

Efforts of excellent program staff and leadership at NIH, excellent reviewers and study sections, excellent and outstanding researchers both working on FSHD and submitting applications to the NIH, and extraordinary efforts of the volunteer health agencies working in this area have not yet enabled FSHD funding to increase at the NIH. It is time for requests, contracts and calls for researcher proposals on FSHD to bootstrap existing FSHD research worldwide.

I am here once again to remind you that FSHD is taking its toll on your citizens. FSHD illustrates the disparity in funding across the muscular dystrophies and recalcitrance in growth over twenty years despite consistent pressure from appropriations language and Appropriations Committee questions, and an authorization from Congress mandating research on FSHD.

The pace of discovery and numbers of leading experts in the field of biological science and clinical medicine working on FSHD are very rapidly expanding. Many leading experts are now turning to work on FSHD not only because it is one of the most complicated and challenging problems seen in science, but because it represents the potential for great discoveries, insights into stem cells and transcriptional processes and new ways of treating human disease.

Fact 5

Patients, professionals, and other parties interested in FSHD can contact us at FSH Society, Inc., BBRI R353, 64 Grove Street, Watertown, MA 02472 USA. Phone (617) 658-7878, fax (617) 658-7879, e-mail: solvefshd@fshsociety.org. Internet: <http://www.fshsociety.org>. 3

Areas of Scientific Opportunity in FSHD that Need NIH Funding

The majority of the international FSHD clinical and research community recently came together at the DHHS NIH NICHD Boston Biomedical Research Institute Senator Paul D. Wellstone MD CRC for FSHD. Almost 90 scientists working on FSHD globally met at the 2009 FSH Society FSHD International Research Consortium, held on Monday, November 9, 2009, and Tuesday, November 10, 2009. The summary and recommendations of the group state the following:

During the past two decades, the FSHD research has made steady progress to unravel the molecular basis of this common muscle disease. The main line of research has focused on the extremely complex (epi)genetic enigma. This complexity has fascinated experts involved in related research. At the present moment the FSHD research field is covering a variety of multidisciplinary and complementary approaches. Although the exact details of the molecular genetic basis of FSHD are still not in place, the general picture is coming into focus. Within one to two (1-2) years, evidence-based intervention strategies are on the drawing-board and trials are planned. To be prepared for this new FSHD era, we need to accelerate the efforts in the following areas --

1. Patients and clinical trials readiness

There is a need for well-characterized registries with uniform data collection. NIH U54 Wellstone MD CRC, NIH registries, and patient organizations are key to this process. These groups and registry and patient organizations are instrumental for:

- a. Work on natural history – identification of phenotype modifiers (genetic and environmental)
- b. Identification of the FSHD2 gene (contraction-independent FSHD)
- c. Bio-banking (cell lines etc.)
- d. Development of tools and assays to measure clinical trials endpoints

2. Epigenetics / Genetics

This line of work will be instrumental to pinpoint the real identity of FSHD1A (chromosome-4-linked cases) and FSHD1B (non-chromosome-4-linked cases). This information will form the basis for evidence-based intervention.

- a. Modifying genes for FSHD1 (large inter-individual variation in symptoms)
- b. Identify the FSHD2 gene (common molecular pathway with FSHD1)
- c. Further work on the chromatin structure / function relationship

3. Biomarkers for clinical therapy

There is obvious need for monitoring intervention.

- a. Systems biology approaches
 - i. transcriptomics, proteomics, metabolomics etc.
- b. In situ (RNA, protein) to detect cellular heterogeneity
- c. Non-invasive monitoring (MRI etc.)

4. Model systems

Urgent need for more specific model systems for mechanistic, intervention work and

advancement to clinical trials.

- a. Cellular models
 - i. Biopsies – for well characterized FSHD cell lines
 - ii. Mosaics -- isogenic and clonal lines
 - iii. Induced pleuropotent stem cells (iPS)
- b. Animal
 - i. Mouse – inducible / humanized mouse etc.
 - ii. Other species

5. Molecular, Cellular and Genomic

- a. myogenesis in normal and FSHD muscle (myoblasts/myotubes)
- b. Cell cycling
- c. Dynamics of muscle satellite cells
- d. RNA iso-forms and alternative splicing (FRG1, DUX4, others)
 - i. genome wide (normal versus FSHD)
- e. Chromatin structure at 4q35
- f. Downstream gene targets

Our request to the NIH Appropriations Subcommittee

We request this year in FY2011, immediate help for those of us coping with and dying from FSHD. We ask **NIH to fund research on facioscapulohumeral muscular dystrophy (FSHD) at a level of \$25 million in FY2011.**

We implore the Appropriations Committee to request that the Director of NIH, the Chair, and Executive Secretary of the federal advisory committee Muscular Dystrophy Coordinating Committee mandated by the MD CARE Act 2008, to increase the amount of FSHD research and projects in its portfolios using all available passive and pro-active mechanisms and interagency committees.

We ask that Congress ask NIH to consider increasing the scope and scale of the existing DHHS U.S. NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers (U54) to double or triple their size – they are financially under-powered as compared to their potential. These centers have provided an excellent catalyst for progress in funding and a greater seriousness in the endeavor of treating muscular dystrophy. We ask Congress to request of NIH the development of mechanisms to help expand work from the center of the NIH Wellstone Centers outward to address needs and priorities of the scientific communities.

Given the knowledge base and current opportunity for breakthroughs in treating FSHD it is inequitable that only four of the twelve NIH institutes covering muscular dystrophy have a handful of research grants for FSHD. We request that the Director of the NIH be more proactive in facilitating grant applications (unsolicited and solicited) from new and existing investigators and through new and existing mechanisms, special initiatives, training grants and workshops – to bring knowledge of FSHD to the next level.

Thanks to your efforts and the efforts of your Committee, Mr. Chairman, the Congress, the NIH and the FSH Society are all working to promote progress in facioscapulohumeral

muscular dystrophy. Our successes are continuing and your support must continue and increase.

Mr. Chairman, thank you for this opportunity to testify before your committee.

Written Testimony of
Family Voices, Inc.
Submitted to the
House Committee on Appropriations,
Subcommittee on Labor, Health and Human Services and Education
Health Resources and Services Administration (HRSA),
Maternal & Child Health Bureau (MCHB)

Sophie Arao-Nguyen, Ph.D.
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I am grateful for this opportunity to submit written testimony on behalf of Family Voices, Inc., an organization of families whose children have special health care needs and/or disabilities. Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

Family Voices respectfully asks the Subcommittee to provide \$10 million in funding for Family-to-Family Information Centers (F2F HICs) for Federal Fiscal Year 2011. In addition, we request that funding for the Title V Maternal and Child Health Services Block Grant be increased to \$730 million for Federal Fiscal Year 2011.

Family-to-Family Health Information Centers

F2F HICs are statewide, family-led information and referral centers that provide families with information about how to obtain and finance health care for their children/youth with special health care needs (CYSHCN), including disabilities and chronic medical conditions like cerebral palsy, epilepsy, or asthma. The Deficit Reduction Act of 2005 mandated that federal grants be provided (\$3 million in FY 2007, \$4 million in FY 2008, and \$5 million in FY 2009) to create a F2F HIC in every state and the District of Columbia by FY 2009. The Patient Protection and Affordable Care Act provided \$5 million in each of fiscal years 2010-2012 to maintain these F2F HICs at their current levels of funding.

The needs of CYSHCN are chronic and complex and, thus, securing and paying for their care is often a struggle. F2F HICs provide life-altering information to families in crisis; simply enrolling in Medicaid for a newborn in need of expensive critical care can be an arduous task. Most of the staff at F2F HICs are members of families whose children have special health care needs. This unique perspective allows them to provide advice, offer a multitude of resources, and tap into a network of other families and professionals for support and information. In addition, they help health care providers to understand the various public programs available for

their patients, and assist in dealing with private insurers. In fact, about one-third of requests to F2F HICs are from health care professionals. The centers also aim to ensure that each child has a “medical home,” and that partnerships are built between health care professionals and the families of CYSHCN, thereby improving the quality of care.

At the present level of funding -- \$5 million total -- each site receives only \$95,700 per year. Although hundreds of thousands of families are being served by F2F HICs, the level of funding is not sufficient to serve all of the families and providers who need assistance in each state. As discussed in more detail below, an increase to \$10 million is needed to assist more families of CYSHCN and health care providers who need these services; to expand training and technical assistance to grantees; and to make these valuable services available to additional regions and populations. Moreover, the health care system navigation function provided by F2F HICs will be of increased importance now that health care reform has been enacted.

There is a great need for Family-to-Family Health Information Centers (F2F HICs).

An estimated 22% of U.S. household with children have at least one child with special health care needs – that is over 10 million children -- and that number appears to be growing. Among these families, 38% do not have adequate insurance to pay for services their children need; 20% of these families pay \$1,000 or more per year in out-of-pocket expenses. These problems are exacerbated among families of ethnic, racial and cultural minorities because their access to coverage and care is significantly more limited.

It is very difficult for families to figure out how to finance their children’s care, given the great expense and complexity of potential funding sources -- private insurance, Medicaid, SCHIP, state Maternal and Child Health programs, the school system – each with different eligibility and coverage criteria. It can also be difficult to find sources of care, given the shortage and maldistribution of pediatric subspecialists.

Additional funding is needed to sustain the current scope of work, and to expand F2F HICs to territories and tribal organizations.

Currently, F2F HICs are being funded at \$5 million dollars. This money funds 51 existing centers, one in each state and one in the District of Columbia, at approximately \$95,700 a year -- barely enough to cover one staff member or two part-time employees, and not enough to serve all the families who need assistance. All states could use more funding to reach more families. States with large populations in particular need larger grants in order to serve the families within their states.

In addition, the number of centers should be expanded to serve territories and Native American populations, which have their own unique health care systems. It is anticipated that over the next several years, 10 new grantees could be established in order to meet the needs of these distinct populations. These new grantees would require operating funds, and would necessitate additional costs for oversight and technical assistance.

Additional funding is needed to provide technical assistance to grantees.

There are currently no designated dollars to provide structured technical assistance to funded F2Fs. A very small amount of the funds remaining after state distributions (\$21,000 in the past year) has been used to assist in planning and coordinating a technical assistance meeting. Substantial technical assistance for developing, assisting and coordinating F2F programs, provided through a national, experienced, family-run organization, in coordination with regional family-run organizations, is needed to grow the capacity and ensure the quality of the F2Fs to best meet the needs of families of CYSHCN navigating complex health care systems.

Health care reform will further necessitate the services of F2F HICs.

Health care reform will require the services of the F2F HICs more than ever, as families whose children have special health care needs attempt to maneuver a new and complex system of insurance and care. The F2Fs HICs are expert in the unique needs of this sizeable population. Family-to-Family Health Information Centers within each state will be the best-positioned organizations to serve as navigators for families of CYSHCN -- a role that has been identified in health care reform bills as necessary to ensure that the goals of the reform are met and maximized.

F2F HICs receive less funding than a comparable educational assistance program-- Parent Training and Information Centers.

Over 25 years ago, the federal government recognized the complexities faced by families whose children need or might need special education services, and created a nationwide system of support and technical assistance for these families -- Parent Training and Information Centers (PTIs).

Families with children who have special health care needs face equal and additional challenges when faced with maneuvering the health care system -- a system much more complex than the special education system, which is governed by one law (IDEA), whereas the health care system consists of a myriad of private and public insurance programs, benefits, waivers, limitations, networks and cost-sharing.

In FY 2009, the PTIs were funded at \$27 million, versus the \$5 million in funding for the F2F HICs, despite the fact that they serve a very similar population.

The F2F HIC program has demonstrated its effectiveness and value.

Although they operate on shoe-string budgets, F2F HICs are able to help many families: from July 2008 to May 2009, the 41 F2F HICs then in existence trained and assisted over 665,000 families of CYSHCN by helping them to navigate community services, partner with health professionals, find financing for care, and access a medical home. In addition, F2F HICs trained and assisted over 320,000 health care professionals in helping families with CYSHCN. On

average, each F2F HIC collaborated with 14 state-level programs and 10 community-based organizations.

The value and potential of F2F HICs has been established by outside evaluators:

“Family-to-Family Centers nationwide provide important information and assistance to families of CYSHN as well as the professionals who care for them, often with very limited staff and resources.”.. *Thomson Medstat, June 2006*

“By helping families to provide a consumer perspective on program and policy issues, F2F HICs are helping states to develop more effective ways to assist families with CYSHCN. Ultimately, the F2F HICs goal is to improve health and functional outcomes for families with CYSHCN. To the extent families understand what is available for their children and use services effectively, outcomes for their children will improve. These benefits go well beyond the children and families. Children whose outpatient needs are met and whose parents are able to meet their daily care needs are less likely to require hospital or emergency room care. Children who obtain home and community long-term care services are less likely to need costly institutional care. Congress has recognized the value of F2F HICs by authorizing funds to establish one in every state. These highly effective organizations require a stable source of funding to sustain outreach and referral services, information development and dissemination, and education and training initiatives.” *Research Triangle Institute, April 2006.*

Perhaps more compelling are the stories of families who have been assisted by F2F HICs. An example is provided from Louisiana, where the F2F HIC assisted a family who had two children with severe disabilities. Both children had private health insurance and Medicaid for secondary coverage. The private health insurance company began requiring their enrollees to use an out-of-state mail-order pharmacy for their regularly renewed medications. This meant that the family was no longer able to use Louisiana Medicaid as a secondary insurer because the out-of-state pharmacy was not a Louisiana Medicaid provider. The family was faced with over \$500 per month in additional costs because they could not access their Medicaid coverage. The Louisiana F2F HIC worked with the state Medicaid Director so that this family could submit the balance of the costs and receive their sorely needed benefits.

For the above reasons, we respectfully request that a \$10 million appropriation be provided for F2F HICs for FY 2011.

Title V Maternal and Child Health Block Grant

As you know, one of the missions of the Title V Maternal and Child Health Block Grant is to serve children with special health care needs. State MCH programs for CYSHCN help to build an infrastructure to ensure the provision of family-centered, community-based coordinated care for children with chronic conditions and disabilities. They have strong connections to pediatric specialists and the best available data on the needs of these children and their families. Due to years of reduced investment, however, the MCH Block Grant is at its lowest funding level since 1993, \$662 million dollars. The program -- and the populations it serves -- deserves increased funding to fulfill its valuable missions. Therefore, Family Voices respectfully requests that the Congress provide \$730 million for the Title V Maternal and Child Health Block Grant program for FY 2011.

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Testimony of
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On
FY 2011 Appropriations for the National Institutes of Health (NIH)

Submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Representative David Obey, Chair
Representative Todd Tiahrt, Ranking Member

April 16, 2010

On behalf of the **Federation of American Societies for Experimental Biology (FASEB)**, I respectfully request an appropriation of \$37 billion for the National Institutes of Health (NIH) in FY 2011. Sustained and predictable public support for biomedical research is needed to accelerate the pace of discovery, improve the health of our nation's citizens, and contribute to the economic revitalization of our country.

As a Federation of 23 scientific societies, FASEB represents more than 90,000 life scientists and engineers, making us the largest coalition of biomedical research associations in the United States. FASEB's mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences, including the research funded by NIH, through service to its member societies and collaborative advocacy. FASEB enhances the ability of scientists and engineers to improve—through their research—the health, well-being, and productivity of all people.

Due to the prior federal investment in NIH, researchers have made critical advances that have saved and improved the lives of millions of Americans and provided doctors with cutting-edge tools to prevent and treat costly and devastating diseases including:

- **Type 2 Diabetes:** In the United States, about 11 percent of adults—24 million people—have diabetes, and up to 95 percent of them have type 2 diabetes. An additional 57 million overweight adults have glucose levels that are higher than normal but not yet in the diabetic range, a condition that substantially raises the risk of a heart attack or stroke and of developing type 2 diabetes in the next 10 years. Researchers have recently demonstrated, based on a decade of data collection, that intensive lifestyle changes aimed at modest weight loss reduced the rate of developing type 2 diabetes by 34 percent in people at high risk for the disease. Intensive lifestyle changes consisted of lowering fat and calories in the diet and increasing regular physical activity to 150 minutes per week. Participants received training in diet, exercise (most chose walking), and behavior modification skills

- **Melanoma:** Drawing on the power of DNA sequencing, NIH researchers identified a new group of genetic mutations involved in the deadliest form of skin cancer, melanoma. This discovery is particularly encouraging because some of the mutations, which were found in nearly one-fifth of melanoma cases, reside in a gene already targeted by a drug approved for certain types of breast cancer. In the United States and many other nations, melanoma is becoming increasingly more common. A major cause of melanoma is thought to be sun exposure; the ultraviolet radiation in sunlight can damage DNA and lead to cancer-causing genetic changes within skin cells
- **Seasonal and Pandemic Flu:** Scientists have identified a small family of lab-made proteins that neutralize a broad range of influenza A viruses, including the H1N1 flu viruses, the 1918 pandemic influenza virus, and H5N1 avian virus. These human monoclonal antibodies, identical to infection-fighting proteins derived from the same cell lineage, also were found to protect mice from illness caused by H5N1 and other influenza A viruses. Because large quantities of monoclonal antibodies can be made relatively quickly, these influenza-specific monoclonal antibodies potentially could be used in combination with antiviral drugs to prevent or treat the flu during an influenza outbreak or pandemic
- **Stroke:** Scientists have identified a previously unknown connection between two genetic variants and an increased risk of stroke, providing strong evidence for the existence of specific genes that help explain the genetic component of stroke
- **Heart Disease:** There has been a 63 percent reduction in deaths from heart disease, and more than one million lives are saved each year by therapies developed to prevent heart attack and stroke
- **Cancer:** Since 2002, the number of deaths from cancer has decreased steadily. In the past 30 years, survival rates for childhood cancers have increased from less than 50 percent to over 80 percent.
- **HIV/AIDS:** This disease has been transformed from an acute, fatal illness to a chronic condition; the prophylactic use of anti-virals prevented almost 350,000 deaths worldwide in 2005. In the U.S., deaths from AIDS dropped nearly 70 percent between 1995 and 2000. Life expectancy for those infected with HIV has increased by ten years.

The completion of the Human Genome Project and the resulting reductions in genome sequencing costs are another example of how the prior investment in research has both dramatically increased the pace of discovery and harnessed the power of technology. Genome sequencing brings us to the threshold of personalized medicine, where knowledge of our own individual genetic makeup can be used to target cures and identify the most effective therapies for individuals. Researchers are at the beginning of a whole new era of pharmacogenomics that will identify methods to tailor treatments and scientifically match therapies to individual circumstances in ways that were inconceivable a few years ago.

Knowledge of an individual's genetic make-up has already been effective in determining which

drugs work best with certain cases of AIDS, breast cancer, acute lymphoblastic leukemia, and colon cancer. The number of new research proposals is expected to expand dramatically as researchers exploit this exciting line of inquiry, yet continued progress toward that goal depends on sustained and predictable funding support for the NIH.

Sustainable Budget Growth Will Maximize the Return on Investment

Additional funding is needed to fully develop the knowledge we have gathered to date and to apply that knowledge in clinical settings. The research engine needs a predictable, sustained investment in science to maximize our return on investment. The discovery process—while producing tremendous value—often takes a lengthy and unpredictable path. Recent experience has demonstrated how cyclical periods of rapid funding growth followed by periods of stagnation are disruptive to training, careers, long range projects, and ultimately to scientific progress. In 2011 and beyond, we need to make sure that the total funding available to NIH does not decline and that we can resume a steady, continuous growth that will enable us to complete President Obama's vision of doubling our investment in basic research.

The most painful consequence of failing to continue the robust investment in research will be the delay in relief to those suffering from the burdens of disease. Long-term plans for federal investment in science facilitate coordination and planning, encourage investments by the private sector, attract new talent, reduce the startup costs of projects, and eliminate the possibility of waste that could result from abrupt termination of valuable scientific investigations.

Prosperity and Quality of Life Are Shaped By Investments in Science

As a nation, we currently find ourselves confronting a number of unprecedented social and economic challenges, and once again our leaders have turned to research in the quest for solutions to these vexing problems. Funds from the *American Recovery and Reinvestment Act* (ARRA) have inspired the creative energies of research teams across the nation. These new resources, coming after many years during which our capacity for research was eroded by flat budgets, are a lifeline for new ideas, research personnel, and progress.

ARRA funding was only appropriated for a two year period, and we face a major shortfall when these funds have been spent. Returning to pre-ARRA funding levels presents a frightening prospect for those whose hopes for a brighter future rest with medical research. It will also be a setback for the scientists who have contributed so much of their time and talent to this quest. It is critical that we invest now to sustain the excitement in research, maximize the return on our prior investments, and continue the innovative pipeline of medical and technological advancements that federal science agencies have always fostered.

Despite the fragile economy, now is not the time to pull back from our historic commitment to investigation and discovery. Our leadership in science and engineering has made us the envy of the world. However, we must nurture our research investment to benefit from the knowledge that we have gained and ensure that continued progress is not curtailed. President Obama has recognized the importance of continuing support for the NIH in his proposed budget for FY2011.

A half-century of public investment in NIH has dramatically advanced the health and improved the lives of Americans and of people around the globe. Unfortunately, millions of Americans and their families still suffer from the ravages of disease and cannot wait for new treatments, therapies, and prevention strategies. Sustained and predictable public support for biomedical research is needed now more than ever. We recognize that this subcommittee has the especially difficult task of providing funding for a wide range of critical human service programs and thank you for your prior support of the research enterprise. Nonetheless, additional resources are needed to pursue the unprecedented level of scientific opportunities available today and uphold the nation's role as a leader in medical research. **Therefore, FASEB recommends an appropriation of \$37 billion for the National Institutes of Health (NIH) FY 2011.**

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Written Testimony for the
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
U. S. House of Representatives
on
FY 2011 Appropriations for NIH

Submitted May 12, 2010

Thank you for the opportunity to provide testimony in support of NIH-funded research. The Federation of Associations in Behavioral and Brain Sciences (FABBS) represents twenty-two scientific societies with an interest in promoting human potential and well-being by advancing the sciences of mind, brain, and behavior. Research covering the spectrum from genes and molecules, to the brain and mind, and to behavior, social relationships, culture and the environment are necessary to provide a full understanding of health and disease.

NIH is supporting research that will lead to ground-breaking discoveries that will improve health and save lives. An essential part of the overall research portfolio is research on the mind, brain, and behavior. Basic and applied research that examines how the mind functions, its relation to behavior and society, and its underlying biology are critically important in understanding, preventing, and treating disease.

Important transformations are occurring in science. Scientists often work at different levels of analysis by examining, for example, the impact of genes on health or alternatively, the influence of culture on health. Both are necessary to address central questions about health and illness. Increasingly, however, scientists are also exploring the margins and bringing to bear multiple disciplines, tools, technologies, and approaches to inform their work. All are necessary if we are to truly understand the human condition and, in turn, enhance human health, potential, and productivity.

The role of emotions, cognitions, and environment in health and illness

NIH is supporting the best research both within and across disciplines to better understand the contributors to illness and disease. In one program of research, investigators are attempting to understand the mechanisms —neural, hormonal, cellular, genetic— by which loneliness gets under the skin to affect health, and importantly, how the mind can modulate these health outcomes. Humans are social beings and spend about 80% of their time, on average, with other people. Much research has shown that people who are socially isolated, or perceive that they are socially isolated, have poorer health outcomes. Specifically, loneliness has been associated with increased duration and extent of illnesses ranging from the common cold to depression to heart disease. The affected factors contributing to these effects include diminished immune system

responses, elevated blood pressure, and even changes in gene expression. This new field of social neuroscience is illuminating how the social environment affects cognition, emotion, personality processes, brain, biology, and health.

Research in this area suggests that the risks associated with developing heart disease that are posed by social isolation may be as high as those posed by high cholesterol, high blood pressure, and even smoking. Research has also shown that perceptions of being alone may be *more* harmful to health than actually being alone. By understanding the mechanisms by which social networks, mental processes, and biology are linked, efforts can be made to translate this work more readily into clinical contexts.

NIH is also supporting highly innovative research to better understand emotions, since emotional states are central to mental and physical health. With funding from the NIH Director's Pioneer Award, one investigator is examining the complex mental and physical processes in emotions. What is the physiological state giving rise to an emotion, and how does the mind make meaning of the physical state? How does the mind control emotions, and what role does context play in emotions? Simply put, emotions may not be simple reflexes that turn on parts of the brain, but are likely much more complex. Emotional disturbances exact a huge toll on patients, and this research has the potential to transform our understanding of a broad area of science.

Complex medical problems require approaches that draw upon a range of scientific areas to address health challenges. These research programs illustrate some of the exciting new work in the mind, brain, and behavioral sciences funded by NIH.

The importance of fundamental research at NIH

NIH investments in basic research are a critical part of the overall research portfolio at NIH. A basic understanding of how cells and genes function is a necessary building block. The same is true for fundamental research in the mind, brain, behavior sciences. As Dr. Collins has noted, NIH's mission is "science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and to reduce the burdens of illness and disability."

We commend NIH for its leadership in developing research initiatives that will build a base of knowledge to inform many public health challenges facing this country— from cancer, heart disease, and HIV to diabetes and childhood obesity. One such initiative, called OPPNET for Opportunity Network, was launched in November 2009 by NIH Director Francis Collins M.D. Ph.D. The new trans-NIH initiative will provide funding for emerging areas in the behavioral and social sciences, similar to the research described above. OPPNET will build upon existing NIH investments to create a body of knowledge about the nature of behavior, the underlying mental and physical processes, and how social factors influence it. As with basic research on genes and molecules, this research is a necessary building block upon which many other advances in science will be possible.

Initiating health-promoting behaviors and maintaining positive changes remain a central question

in health research. Behavior has a pervasive impact on health, and despite advances in the science, significant and sustained behavior change remains elusive. Given its importance, NIH is investing in a new cross-NIH and cross-disciplinary research agenda on the basic science of behavior change. The goal is to “radically move this science forward.” Key themes identified by scientists for a new research agenda include integrating the science at multiple levels (i.e., brain, person, and environment) such that behavior changes can be seen at a population level. Also, there is a need to better understand the basic mechanisms of behavior change, examine key opportunities for changing behavior at various points in the lifespan, and to target multiple behaviors at once since unhealthy behaviors can have common underlying processes. The *Science of Behavior Change* is one of seven new NIH Common Fund initiatives, one in which NIH is pushing science to cross traditional disciplinary and topical boundaries. These basic science initiatives are supported by multiple Institutes across NIH.

Using its modest budget, the Office of Behavioral and Social Sciences Research (OBSSR), created by Congress in 1993, continues to play a key role in coordinating and facilitating initiatives across the Institutes. In addition, OBSSR identifies new and promising opportunities for the behavioral and social sciences to help advance NIH’s mission. Projects underway or in the pipeline include improving our knowledge of the interplay among behavior, environmental factors (particularly social environment), and genomic/epigenetic factors in health illness; applying complex systems modeling to understanding and ameliorating health disparities; promoting initiatives in health literacy and community-based participatory research in medically underserved populations; and identifying prevention strategies for health care that are both grounded in science and cost-effective.

Translating Basic Behavioral and Social Science Discoveries

NIH’s investments in basic research will lead to discoveries that can be translated for use in clinical settings. Indeed, NIH is increasingly turning its attention to this process. As NIH Director, Dr. Collins has made this one of his five priorities. Likewise, behavioral and social scientists at NIH are examining the opportunities and challenges for translating promising findings from these sciences for use in community and clinical care settings. For example, efforts to translate basic behavioral and social science research findings into behavioral interventions to reduce obesity will inform a critical public health challenge facing this country. Translational research will improve our ability to convert basic science discoveries into meaningful community and clinical interventions.

Building Research Capacity in All Sciences

The sciences of mind, brain, and behavior are critical to the health and well-being of our nation’s citizens and, in turn, the nation’s prosperity. The development and progression of many illnesses and health problems such as heart disease, diabetes, and obesity depend on behavior. In addition, advancing knowledge in the behavioral and social sciences is increasingly requiring technical expertise. For example, to understand the workings of the mind, scientists must be able to utilize fMRI, MEG, and EEG tools. Investing in research and training in the behavioral and social sciences, as well as research and training that involve behavioral and social scientists and cross

disciplinary boundaries, will address current needs and help prepare the next generation of researchers. The nation must build capacity in all sciences and at all educational levels to address health needs and remain competitive.

FY 2011 Funding Request for NIH

This is an incredible time for science. Investments by Congress in 2009 and a commitment by the administration to science are allowing mid-career and senior scientists to remain at work on complex health problems facing our society, while also attracting a new generation of scientists to become engaged and excited about careers in science. In addition, new discoveries within scientific disciplines and across disciplinary boundaries, are keeping the U.S. competitive. These investments are making a difference back home, both in dollars that support research positions at local universities and in the innovations that improve health throughout our communities.

Investments in science will continue to spur economic growth now and well into the future. We urge this Subcommittee to support \$35 billion for the National Institutes of Health in the FY 2011 appropriation.

**Friends of the Health Resources and Services Administration
(HRSA)**

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**Testimony of the Friends of the HRSA
Concerning the Health Resources and Services Administration's Budget for Fiscal Year 2011
House Appropriations Subcommittee on Labor, Health and Human Services and Education
Submitted for the Record
April 16, 2010**

The Friends of the Health Resources and Services Administration (HRSA) is a non-profit and non-partisan alliance of more than 170 national organizations, collectively representing millions of public health and health care professionals, academicians and consumers. The coalition's principal goal is to ensure that HRSA's broad health programs have continued support in order to reach the populations presently underserved by the nation's patchwork of health services.

Through its programs in every state and thousands of communities across the country, HRSA is a national leader in providing health services for individuals and families throughout the country and serves as a health safety net for the medically underserved including the 86.7 million Americans who were uninsured for some or all of 2007-2008 and 50 million Americans who live in neighborhoods where primary health care services are scarce. **To respond to these challenges, it is the best professional judgment of the members of the Friends of HRSA that the agency will require an overall funding level of at least \$9.15 billion for fiscal year (FY) 2011.**

We are appreciative of your past efforts to provide increased support for the Health Resources and Services Administration (HRSA) in FY 2010. While recognizing the constraints of the current budgetary climate, our request of \$9.15 billion for HRSA in FY 2011 reflects the minimum amount necessary for the agency to adequately meet the needs of the populations it serves. The relatively level funding HRSA has received over the past several years has undermined the ability of its successful programs to grow; much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and health care infrastructure.

Our \$9.15 billion FY 2011 HRSA funding request is based upon recommendations provided by coalition members to support HRSA programs including:

- **Health Professions** programs support the education and training of primary care physicians, nurses, dentists, optometrists physician assistants, nurse practitioners, public health personnel, mental and behavioral health professionals, pharmacists, and other allied health providers; improve the distribution and diversity of health professionals in medically underserved communities; and ensure a sufficient and capable health workforce able to provide care for all Americans and respond to the growing demands of our aging and increasingly diverse population. In addition, the Patient Navigator Program helps individuals in underserved communities who suffer disproportionately from chronic diseases navigate the health care system.
- **Primary Care** programs support more than 7,000 community health centers in every state and

territory, improving access to preventive and primary care in geographically isolated and economically distressed communities. In addition, the health centers program targets populations with special needs, including migrant and seasonal farm workers, homeless individuals and families, and those living in public housing.

- Maternal and Child Health Flexible Maternal and Child Health Block Grants, Healthy Start and other programs provide services, including prenatal and postnatal care, newborn screening tests, immunizations, school-based health services, mental health services, and well-child care for more than 34 million uninsured and underserved women and children not covered by Medicaid or the Children's Health Insurance Program, including children with special needs.
- HIV/AIDS programs provide assistance to metropolitan and other areas most severely affected by the HIV/AIDS epidemic; support comprehensive care, drug assistance and support services for people living with HIV/AIDS; provide education and training for health professionals treating people with HIV/AIDS; and address the disproportionate impact of HIV/AIDS on women and minorities.
- Family Planning Title X programs provide reproductive health care and other preventive services for more than 5 million low-income women at over 4,500 clinics nationwide. These programs improve maternal and child health outcomes, prevent unintended pregnancies, and reduce the rate of abortions.
- Rural Health programs improve access to care for the 60 million Americans who live in rural areas. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program, and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas.
- Special Programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program the C.W. Bill Young Cell Transplantation Program, and National Cord Blood Inventory. Strong funding would facilitate an increase in organ, tissue and blood cell donations and transplantations.

Greater investment is necessary to sufficiently fund HRSA services and programs that continue to face increasing demands. We urge you to consider HRSA's role in building the foundation for health service delivery and ensuring that vulnerable populations transition smoothly into a new health system to receive quality health services, while continuing to strengthen our nation's health safety net programs. By supporting, planning for and adapting to change, we can build on the successes of the past and address new gaps that emerge as a result of health system reform.

We appreciate the Subcommittee's hard work in advocating for HRSA's programs in a climate of competing priorities. The members of the Friends of HRSA thank you for considering our FY 2011 request for \$9.15 billion for HRSA in the FY 2011 Labor, Health and Human Services and Education Appropriations bill and are grateful for this opportunity to present our views to the Subcommittee.

AIDS Action
 AIDS Project Los Angeles
 Alliance for Academic Internal Medicine
 American Academy of Family Physicians
 American Academy of Nurse Practitioners
 American Academy of Pediatrics
 American Academy of Physician Assistants
 American Association of Colleges of Nursing
 American Association of Colleges of
 Osteopathic Medicine
 American Association of Colleges of Pharmacy
 American Association of Colleges of Podiatric
 Medicine
 American College of Preventive Medicine
 American Congress of Obstetricians and
 Gynecologists
 American Dental Education Association
 American Dental Hygienists' Association
 American Heart Association
 American Hospital Association
 American Medical Student Association
 American Medical Women's Association
 American Nurses Association
 American Optometric Association
 American Physical Therapy Association
 American Podiatric Medical Association
 American Psychological Association
 American Public Health Association
 American School Health Association
 American Society for Clinical Pathology
 Association of Academic Health Centers
 Association of Departments of Family Medicine
 Association of Family Medicine Residency
 Directors
 Association of Minority Health Professions
 Schools
 Association of Organ Procurement
 Organizations
 Association of Professors of Medicine
 Association of Program Directors in Internal
 Medicine
 Association of Public Health Laboratories
 Association of Schools of Public Health
 Association of State and Territorial Directors of
 Nursing
 Association of State and Territorial Health
 Officials
 Association of the Clinicians for the
 Underserved
 Association of Women's Health, Obstetric and
 Neonatal Nurses
 Charles Drew University of Medicine and
 Science
 Clerkship Directors in Internal Medicine
 Coalition for Health Services Research
 Communities Advocating Emergency AIDS
 Relief Coalition
 Consortium of Social Science Associations
 Council on Social Work Education
 Emergency Nurses Association
 Family Voices
 HIV Medicine Association
 Meharry Medical College
 Morehouse School of Medicine
 National AHEC Organization
 National Association of Community Health
 Centers
 National Association of County and City
 Health Officials
 National Association of Local Boards of
 Health
 National Association of People with AIDS
 National Association of Public Hospitals and
 Health Systems
 National Association of Social Workers
 National Council on Diversity in the Health
 Professions
 National Hispanic Medical Association
 National League for Nursing
 National Rural Health Association
 North American Primary Care Research Group
 Physician Assistant Education Association
 Planned Parenthood Federation of America
 Prevent Blindness America
 Pulmonary Hypertension Association
 Ryan White Medical Providers Coalition
 Society for Public Health Education
 Society of General Internal Medicine
 Society of Teachers of Family Medicine
 The AIDS Institute

Testimony of the Friends of NICHD
 Fiscal Year 2011 Appropriations -- Eunice Kennedy Shriver National Institute of Child Health and Human Development
 April 12, 2010

Submitted by: Laura Kaloi, Chair, Friends of NICHD, National Center for Learning Disabilities
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The Friends of the National Institute of Child Health and Human Development (NICHD) is a coalition of more than 100 organizations, representing scientists, physicians, health care providers, patients, and parents, concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to submit testimony to support the extraordinary work of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.

We would like to thank Chairman Obey, Ranking Member Tiahrt, and the Congress for its continued support of the National Institutes of Health (NIH) and interest in building on the investments made in predictable and sustained, long-term growth in NIH funding in the FY 2011 budget and beyond. **To ensure that progress in basic, translational and clinical research is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting a FY 2011 appropriation of at least \$35 billion, an increase of \$2.6 billion for NIH.**

The Coalition has a particular interest in the important research conducted and supported by the NICHD. Since its establishment in 1963, the NICHD has made great strides in meeting the objectives of its broad biomedical and behavioral research mission. The NICHD mission and portfolio includes a focus on women's health and human development, including research on child development, before and after birth; maternal, child, and family health; learning and language development; reproductive biology and population issues; and medical rehabilitation.

Although the NICHD has made significant contributions to the well-being of children, women, and families, much remains to be done. With sufficient resources, the NICHD could build upon the promising initiatives described in this testimony and produce new insights into human development and solutions to health and developmental problems for the world and for the nation – including the families living in your districts. **For FY 2011, the Friends of NICHD support an appropriation of at least \$1.495 billion for NICHD.**

New Discoveries

Adding to its strong record of progress over the past 45 years, recent advances by the NICHD have contributed to the health and well-being of our nation and world. Several highlights are:

Tracking Brain and Behavioral Development: The NICHD is one of the leading Institutes in the NIH Magnetic Resonance Imaging (MRI) Study of Normal Brain Development. The study tracks brain and behavioral development in 500 healthy children from diverse backgrounds birth to age 18. The latest findings show that children appear to have reached adult levels of performance on basic cognitive and motor skills by age 11 or 12. Long-term, the goal is to link these behavioral data to MRI scans of the children's brains. Together, the two data sets will allow researchers to view how the brain grows and reorganizes itself, and to explore the structural changes. The database will also serve as a reference to better understand what goes wrong in children with genetic disorders, language and learning difficulties, prenatal exposure to alcohol or drugs or other brain injury.

Preterm Birth Risk Factors: Researchers funded by the NICHD identified DNA variants in mothers and fetuses that appear to increase the risk for preterm labor and delivery. The current findings add to the evidence that individual genetic variation may account for why preterm labor occurs in some pregnancies and not in others. The findings may one day lead to new strategies to identify those at risk for preterm birth, and to ways to reduce the occurrence of preterm birth among those at risk.

Treating Mild Gestational Diabetes Reduces Birth Complications: NICHD funded researchers found the first conclusive evidence that treating pregnant women who have even the mildest form of gestational diabetes can reduce the risk of common birth complications among infants, as well as blood pressure disorders among mothers. Specifically, women treated for mild gestational diabetes had smaller, leaner babies less likely to be overweight and less likely to experience shoulder dystocia, an emergency condition in which the baby's shoulder becomes lodged inside the mother's body during birth. Treated mothers were also less likely to undergo cesarean delivery, to develop high blood pressure during pregnancy, or to develop preeclampsia, a life-threatening complication of pregnancy that can lead to maternal seizures and death.

Future Research Opportunities

Although the studies mentioned above have unquestionably made significant contributions to the well-being of our children and families, there is still much to discover about ways to improve health, learning, and quality of life. Progress in the following research areas can only be achieved with adequate federal investments.

Severe, early adverse pregnancy outcomes: Women with severe, early adverse pregnancy outcome, such as multiple losses, demises, and severe preeclampsia, are at increased risk for long-term chronic health problems, including hypertension, stroke, diabetes, and obesity. Studies have shown that women who have had preeclampsia are more likely to develop chronic hypertension, to die from cardiovascular disease and to require cardiac surgery later in life. In addition, approximately 50% of women with gestational diabetes will develop diabetes later in life. Pregnancy can be considered as a window to future health and the immediate post-pregnancy period provides a unique opportunity for prevention of chronic diseases later in life. Studies to identify women at risk for long term morbidity, and to develop strategies to prevent long term adverse outcomes in these women are urgently needed.

Preterm Birth: Preterm birth is a serious and growing public health problem that affects more than 500,000 babies each year. It is the leading cause of neonatal death and about half of all premature births have no known cause. A key strategy recommended by the Institute of Medicine and experts convened for the Surgeon General's Conference on the Prevention of Preterm Birth is to create integrated transdisciplinary research centers to build the knowledge base needed for development of effective interventions to prevent prematurity. These new centers would serve as a national resource for investigators to design new research approaches and strategies to address the serious and growing problem of preterm birth.

National Children's Study: The National Children's Study is the largest and most comprehensive study of children's health and development ever planned in the United States. Currently, the "vanguard centers" are recruiting pregnant women and over 150 children have been born into the study. When fully implemented, this study will follow a representative sample of 100,000 children from across the United States from before birth until age 21. The data generated will inform the work of scientists in universities and research organizations, helping them identify precursors to

disease and to develop new strategies for prevention and treatment. Identifying the root causes of many childhood diseases and conditions, including preterm birth, asthma, obesity, heart disease, injury and diabetes, will reduce health care costs and improve the health of children. The Friends of NICHD thank the Committee for funding the NCS through the NIH Office of the Director in FY 2010, and urge the Committee to provide \$194.4 million for the Study in FY 2011.

Newborn Screening Translational Research Network: The network is designed to improve newborn screening, the care of patients with disorders identified through screening, and deepen understanding of conditions for which screening should be made available. By contributing to our understanding of patients with genetic diseases, this network will accelerate research in diseases related to newborn screening and greatly improve the process by which public health decisions are made about the expansion of newborn screening.

Unraveling Genetic Basis of Autism: NICHD is capitalizing on advances in genetics research by participating in the Autism Genome Project (AGP), a public-private collaboration involving more than 120 scientists and 50 institutions in 19 countries. The first study to emerge from AGP implicated components of the brain's glutamate chemical messenger system and a previously overlooked site on chromosome 11. Based on 1,168 families with at least two affected members, the genome scan also adds to evidence that tiny, rare variations in genes may heighten risk for autism spectrum disorders. The spectrum of disorders collectively known as autism affects as many as one in 150 Americans resulting in impaired thinking processes, emotional and social abilities, and motor control. So far, the only known cause of autism for which there is a verifiable blood test is Fragile X; further research on this disorder would provide understanding of the function of this gene (FMR1) as well as others that cause autism. With NIH support, the AGP is pursuing studies to identify specific genes and gene variants that contribute to vulnerability to autism. These include explorations of interactions of genes with other genes and with environmental factors, and laboratory research aimed at understanding how candidate susceptibility genes might work in the brain to produce the disorders.

Education and School Readiness Research: NICHD continues to build its portfolio of research on how children acquire the emotional, social and academic skills necessary to succeed in school and beyond; however more work is needed in four particular areas: (1) Neurological processing disorders – how they impact learning and literacy, particularly in reading comprehension for grades 4-8, so that early intervention may improve learning and academic outcomes for young adults. (2) Learning delays and language development – how to distinguish if they are caused by language barriers versus possible learning disabilities in school-age children. (3) Math disabilities – where they reside in the brain, how they impact learning over time and what we can do to remediate and intervene with those who have them. (4) School readiness – how to develop better measures of the social and emotional bases which will inform our early education programs. The combination of study in these four areas will help inform the nation's education and innovation agenda to support and grow a competitive workforce.

Contraceptive Research and Development: Nearly one-half of all pregnancies in the U.S. are unintended at the time of conception. Many women have difficulty in maintaining correct and consistent use of contraception across the approximately three decades of their reproductive lives when they are not seeking to become pregnant. NICHD's support for contraceptive research and development is crucial for efforts to prevent unintended pregnancies. NICHD has already expressed

interest in studying the efficacy and safety of hormonal contraceptives among overweight and obese women. This research would help to fulfill a crucial need in the scientific community to assess the safety of and to identify the causes of decreased effectiveness of oral contraception among this population. Other opportunities and research priorities in the area of contraceptive development include the need for non-hormonal contraception, post-coital contraception and multipurpose technologies that would prevent both pregnancy and sexually transmitted infections.

Intellectual and Developmental Disabilities: Ongoing support of the research in mental retardation and developmental disabilities being undertaken at the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (IDDDRC) is essential. Many disorders are being studied by the IDDDRC such as Down syndrome, Fragile X syndrome, Rett syndrome, and autism. Genetic and biomedical advances over the past few years hold the promise for understanding the threats to healthy and full development and ultimately to the prevention and amelioration of the impact of many disabilities.

Obesity: NICHD is integrally involved in research into the origins of obesity in childhood. Next to tobacco use, diet and exercise represent the areas in which prevention efforts will have the greatest impact in reducing the socioeconomic and societal burdens of the obesity epidemic. More developmental research needs to be focused on understanding the interplay among behavioral, social and physical environment, and biological factors that lead to obesity so that effective and appropriate interventions can be developed earlier in the life cycle.

Rehabilitation Research: The NICHD houses the National Center for Medical Rehabilitation Research (NCMRR). This Center fosters the development of scientific knowledge needed to enhance the health, productivity, independence, and quality-of-life of people with disabilities. A primary goal of Center-supported research is to bring the health related problems of people with disabilities to the attention of the best scientists in order to capitalize upon the myriad advances occurring in the biological, behavioral, and engineering sciences.

SIDS: Though the NICHD has made remarkable progress in reducing the rate of SIDS, SIDS remains the leading cause of death in infants from one month of age to one year. More research and public education is needed to address the large number of babies dying of asphyxiation and suffocation in unsafe adult bed-sharing situations. Additional support is also needed to expand the work of NICHD's Stillbirth Collaborative Research Network, where for the first time we are finding answers that may ultimately lead to prevention of many of these 26,000 devastating losses, many of which are late term and yet unexplained.

Conclusion

The potential contributions of the Institute to the lives of countless individuals are limited only by the resources available for carrying out its vital mission. **This is why the Friends of NICHD ask you to provide an appropriation of \$1.495 billion to the Institute.** Our nation and the world will continue to benefit from your promise to improving health and scientific advancement long after the doubling effort is over.

We thank you, Mr. Chairman, and the Committee, for your support of the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and thank you for the opportunity to share these comments.

Written Testimony

FY11 Funding: National Institute for Dental and Craniofacial Research

Prepared for presentation to the U.S. House of Representatives
Appropriations Subcommittee on
Labor, Health & Human Services, Education, and Related Agencies

Submitted By:

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April 16, 2010

Mr. Chairman and distinguished Members of the Subcommittee, the members of the **Friends of the National Institute of Dental and Craniofacial Research (FNIDCR)**, a leading broad-based coalition of individuals, academic institutions, patient advocate groups, dental societies, and corporations, that understands the importance of dental, oral and craniofacial health to our society, are requesting that FY11 funding for the **National Institute of Dental and Craniofacial Research (NIDCR)** be appropriated at our recommended level of \$480 million.

Currently, FY10 funding for NIDCR is \$413,236,000. This is a welcomed 2.6% increase from FY09's funding level. In addition, the American Recovery and Reinvestment Act of 2009 included \$10 billion in aid to the National Institutes of Health (NIH) of which approximately \$101.8 million was appropriated to NIDCR over FY09 and FY10. FNIDCR is grateful for this unprecedented financial support of medical research that has helped make-up for the stagnated funding levels of fiscal years 2004-08.

Amid a challenging budgetary environment, the administration's FY2011 budget request calls for NIDCR funding to be \$423,511,000, a 2.48% increase. This increase is appreciated; however, it is simply inadequate for the following reasons:

1. It is not enough to sustain the job creation and biomedical research initiated by ARRA.
2. There are projected budget reductions for NIH and its Institutes in fiscal years 2012 and 2013 that would reduce funding to FY08 levels of the previous administration.
3. Although NIH's budget has doubled since 1998, NIDCR's budget has not. In fact, NIDCR's percentage of total NIH funding has decreased 13% since 1998, from 1.53% to 1.33%, its lowest percentage in a decade.

Therefore, FNIDCR strongly recommends a return to NIDCR being funded at 1.53% of NIH's total proposed FY2011 budget, or \$480 million, which will address the three points of concern above and will create a sustainable funding path going forward.

NIDCR: A Renown Leader in Research

For 62 years, NIDCR has been the leading sponsor of research and research training in biomedical and behavioral sciences. Its mission is to *"improve oral, dental and craniofacial health through research, research training, and the dissemination of health information."*

NIDCR meets its mission by:

- Performing and supporting basic and clinical research;
- Conducting and funding research training and career development programs to ensure an adequate number of talented, well-prepared and diverse investigators is sustained;
- Coordinating and assisting relevant research and research-related activities among all sectors of the research community; and
- Promoting the timely transfer of knowledge gained from research and its implications to health professionals, researchers, and policy-makers; and on the overall well-being of our society.

In addition, NIDCR's Gold Standard Peer Review System ensures that taxpayers' dollars are being utilized in a wise, effective and productive manner.

NIDCR Research Benefits Society

Proper federal funding of NIDCR will transform the future of medical and dental practice to the benefit of our society and ease the burden on our nation's healthcare system. Examples of where NIDCR research has and will benefit society are:

Tooth Decay: Fluorides and sealants have cut the rate of the number of American adults, aged 45 and older, who are without teeth by more than half since the 1950s. Government investment in oral health research saved Americans \$3 for every \$1 invested.

Oral Cancer Detection: In his February 24, 2009 speech to a Joint Session of Congress, President Barack Obama spoke of a new effort to conquer cancer by seeking a cure in our lifetime. Oral cancer affects 38,000 Americans each year and approximately 22 Americans die each day from it. Survival rates are among the lowest of all the major cancers. It is difficult to detect and hard to predict its outcome. However, if detected in early stages, the five-year survival rate is 83 percent. NIDCR-supported research has yielded initial success with developing new diagnostic techniques that can lead to early detection and life-saving interventions. For example, oral cancer is the first cancer to have its biomarkers mapped using Salivary Diagnostics (see below), and the presence of these biomarkers resulted in an early diagnosis of oral cancer 93 percent of the time. Furthermore, as a testament to scientific discoveries, oral researchers have confirmed that oral cancer (traditionally thought of as being driven by extensive use of tobacco and alcohol) possesses a strong and growing link to Human Papilloma Virus (HPV).

Salivary Diagnostics. The promising prospect of using saliva as a diagnostic fluid to identify a number of emerging diseases, such as cancer, HIV/AIDS, and cardiovascular disease, is an example of the type of cutting-edge research being conducted and supported by NIDCR. Salivary Diagnostics, a non-invasive process, possesses advantages over traditional blood testing, including the absence of needles and the ability to be administered on-the-spot, yielding results in 10 minutes.

Genome-wide Association Studies: NIDCR is supporting the first genome-wide association studies, or "GWAS," on cleft lip/cleft palate and dental caries. This is being done in collaboration between epidemiologists, geneticists, informatics experts, and environmental scientists. The studies offer significant potential for understanding the molecular and genetic basis of cleft lip/cleft palate and dental caries with the goal of improving the ability to predict and manage them by providing the first comprehensive compilation of the biological instructions required to construct the middle region of the human face and to define the genetics that create its developmental disorders, according to NIDCR.

Moreover, NIDCR research benefits millions of Americans with:

- Periodontal Disease
- Chronic Dry Mouth
- Chronic Facial and Oral Pain, and
- Bone and Cartilage Regeneration

NIDCR Research Makes a Difference in People's Lives

Because FNIDCR is a broad-based coalition of members, we are able to share first-hand perspectives from across the spectrum of the oral health community.

National Foundation for Ectodermal Dysplasias:

For several decades, individuals affected by ectodermal dysplasia (ED) have benefited from NIDCR-funded research using osseointegrated implants to correct problems with edentulism. That research was further validated by a recent retrospective study that concluded that such implants continue to be a safe and effective treatment. While former research is of great interest, it is the need for additional research that must be given consideration. For example, there has not been substantive research which supports or negates the value of materials used for augmentation of the alveolar ridge prior to placement of implants. As a result, patients are often the "guinea pigs" for clinicians, subjecting the patient to augmentation, failure, or infection. While NIDCR has been invaluable in moving ectodermal dysplasia research forward, additional funding is necessary to help address past research funding shortfalls to meet the mission of NIDCR.

Sjogren's Syndrome Foundation:

NIDCR has given much-needed hope to approximately four million Americans

who suffer from Sjögren's syndrome, the second most common autoimmune connective tissue disease. Sjögren's affects the moisture-producing glands, resulting in dry eye and dry mouth, and can involve any body organ or system leading to serious health consequences and a major impact on quality of life. Sjögren's is a disease that crosses many specialties and was largely ignored by investigators until the NIDCR established a Sjögren's clinic and became a leader to catalyze research into this complex disease. Recently, NIDCR funded an international registry that will help us better understand Sjögren's and offer bio-specimens to researchers from around the world. NIDCR also issued a Request for Applications in Sjögren's that has jumpstarted critical areas of research such as identification and elucidation of salivary and serum biomarkers and immune and genetic factors that contribute to disease development. NIDCR has helped make scientific workshops possible on topics such as Sjögren's and lymphoma, which most frequently occurs in the salivary glands, leading to greater interest in this topic and collaborations among Immunologists, Oncologists, and Pathologists. Thanks to the active leadership of NIDCR, Sjögren's syndrome is finally receiving the recognition it deserves as a leading autoimmune disease and is on the verge of novel discoveries during this new era of medical research.

University of Maryland College of Dental Surgery:

Maryland's research thrusts are oropharyngeal cancer, a leading cause of death; chronic orofacial pain, and emerging as well as disfiguring infections, including MRSA. At Maryland, NIH-NIDCR support constitutes the backbone for fulfilling its mission to nurture new and to stimulate existing talent in these important areas of unmet need. It provides the resources to develop and maintain a state-of-the-art research infrastructure that is globally competitive and signals to the rest of the world the commitment of the U.S. to reduce the burden of disease for all people. It provides the knowledge for advancing professionals that will offer first-rate care to patients. NIH-NIDCR funding also contributes to Maryland's research training workforce pipeline in the form of training grants so that new investigators and related personnel can enter this field of discovery. Finally, it enables Maryland, by means of science, to develop and launch exciting new programs that improve the access to dental care while fostering a culture for better and safer dental treatments for all Americans.

University of Michigan School of Dentistry:

Research and discovery is deeply embedded in the culture of the University of Michigan School of Dentistry. It has consistently ranked among the top 3 schools in receipt of NIDCR grant awards over the past 5 years, during which NIDCR has provided approximately 68% of total research funding. Focused on a broad range of oral health issues, the School of Dentistry has identified its research strengths through theme groups that are predominately funded through NIDCR, including Developmental Craniofacial Biology, Neurobiology, Tissue Engineering and Regeneration, Cancer Biology and Microbiology/Immunology/Inflammatory Diseases. NIDCR support of our basic and clinical research programs has enabled The School's scientists to make a tangible positive difference in the

health and welfare of the citizens of the state of Michigan and the broader community nationwide. Major scientific impacts resulting from this funding include: uncovering the biological basis of the relationship between periodontal disease and diabetes; development of a method of gene delivery that appears safe for regenerating tooth-supporting periodontal tissues; advancing the understanding of inherited enamel defects; and the development of biologic substitutes for regenerating tissues and organs that can be then transplanted during reconstructive surgery. NIDCR has enabled the University of Michigan School of Dentistry to make a difference in the lives of those it serves.

Funding Medical Research Generates Economic Activity

We maintain that an increase in FY11 NIDCR funding will help sustain the increased economic activity, job creation, and biomedical research advancement generated by ARRA throughout the nation. According to NIDCR, the \$101.8 million NIDCR ARRA funding supported 136 new or competing two-year research and research training grants and 109 administrative supplements to scientists with active NIDCR grants. NIDCR ARRA grant awardees were from 33 states.

Moreover, non-ARRA NIDCR-funded research has a presence in 200, or 46 percent, of Congressional Districts and in 45 states. Therefore, a significant portion of NIDCR-funded research occurs off the NIH campus and around the country.

Oral Health Disparities Centers

Finally, through community-based disparities research funded by NIDCR, a difference is being made in meeting the health needs of our nation's low-income, underserved, and high-risk populations. Sadly, this need was made apparent with the tragic passing of 12-year-old Deamonte Driver who died from a tooth infection in 2007. In FY09, for example, NIDCR functionally integrated three separate Health Disparity Centers at the University of California, San Francisco, University of Colorado, Denver, and Boston University to explore ways to prevent early childhood caries (ECC).

RECOMMENDATION

Proper funding of NIDCR is essential to the overall health and well-being of our fellow Americans. We firmly contend that medical discoveries and advances from NIDCR funding lead to improvements in dental practices and change the scope of public health policies across the nation. Whether it is detecting a clear link between bacteria in the mouth and heart disease—or discovering how saliva can be used to detect early indications of disease—we all benefit when we make oral health research a priority. Therefore, based upon the merits of the research conducted by NIDCR, and its demonstrated benefits to the lives of countless Americans, **we respectfully request the Subcommittee fund NIDCR at \$480 million for FY11, or 1.53% of NIH's total proposed budget, so that it can realize the full potential of its worthy mission and sustain the scientific research that will emerge as a result of ARRA.** Thank you for the opportunity to present our written testimony before the Subcommittee.

**The Friends of the National Institute on Aging
Testimony on FY 2011 National Institutes of Health Appropriations**

**Submitted to:
House Subcommittee on Labor, Health and Human Services,
Education and Related Agencies**

**Submitted by:
Kimberly D. Acquaviva, PhD, MSW
The Friends of the National Institute on Aging, Chair
202-994-7735 acquava@gwu.edu**

April 12, 2010

Chairman Obey and members of the Subcommittee, thank you for the opportunity to provide testimony regarding the crucial role of the National Institute on Aging (NIA) within the National Institutes of Health (NIH) and the need for increased appropriations in the Fiscal Year 2011 budget to ensure sustained, long-term growth in aging research

The Friends of the NIA is a coalition of 50 academic, patient-centered and not-for-profit organizations that conduct, fund or advocate for scientific endeavors to improve the health and quality of life for Americans as we age. As a coalition, we support the continuation and expansion of NIA research activities and seek to raise awareness about important scientific progress in the area of aging research currently guided by the Institute.

My testimony today demonstrates the relevance of the work of the NIA to each and every American, as well as opportunities for future progress that are dependent on Congressional action to build upon the unprecedented \$10.4 billion in the American Recovery and Reinvestment Act (ARRA) for NIH research and training activities in Fiscal Year 2011.

The Relevance of the Work of the NIA

NIH is the primary funder of biomedical research in this country and as such, NIA leads the Federal effort to advance biomedical and behavioral research in aging. The National Institute on Aging (NIA) leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults. NIA's mission is three-fold: (1) Support and conduct genetic, biological, clinical, behavioral, social, and economic research related to the aging process, diseases and conditions associated with aging, and other special problems and needs of older Americans; (2) Foster the development of research- and clinician-scientists for research on aging; and (3) Communicate information about aging and advances in research on aging with the scientific community, health care providers, and the public. The NIA carries out this mission by supporting both extramural research at universities and medical centers across the United States and vibrant intramural research at the NIA's laboratories in Baltimore and Bethesda, Maryland. The work of the NIA focuses not only on diseases and conditions of aging but also on the processes underlying the aging process itself and as such, the research conducted

by NIA-funded scientists has relevance for each and every person in America, regardless of age.

Forward Momentum: ARRA Funding and the NIA

The bolus of funding provided by the American Recovery and Reinvestment Act (ARRA) has made it possible for NIA-funded researchers to make progress towards key research questions related to health and aging. As a result of ARRA funding, NIA-funded scientists have been able to intensify their research efforts in areas of critical importance to aging and health, including but not limited to the following:

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| Understanding how Alzheimer's Disease develops and progresses | Investigating the ways in which Alzheimer's Disease (AD) and vascular disease may adversely affect one other in the hopes of identifying strategies for preventing dementia. ¹ |
| | Examining the ways that energy metabolism influences brain aging by looking for correlations among brain imaging patterns, dementia, and metabolic measures in aging and in people with AD. ² |
| Identifying genetic and other risk factors for Alzheimer's Disease | Using genome-wide association studies to compare the genomes of individuals with and without AD to identify potential genetic risk. ³ |
| Seeking new ways of screening for and detecting Alzheimer's Disease | Identifying best practices for cerebrospinal fluid sample collection and attempting to identify AD biomarkers in cerebrospinal fluid before the onset of symptoms. ⁴ |
| | Comparing the effectiveness of brain imaging and blood biomarkers to diagnose AD. ⁵ |
| Discovering possible prevention and treatment strategies for Alzheimer's Disease | Elucidating the long-term effect of naproxen and other NSAIDS on cognitive health by following participants in the Alzheimer's Disease Anti-inflammatory Prevention Trial (ADAPT) to. ⁶ |
| | Determining whether compounds that manipulate the histone code may have therapeutic value for AD and other neurological disorders. ⁷ |
| Enhancing neuroimaging methods and tools | Developing software to simplify the analysis of complex brain-image data relating to the structure and function of the human brain. ⁸ |
| | Developing a "network diagram" that links genetic information with underlying brain circuitry in the neural systems controlling behavior and emotion to improve our understanding of the connectivity of circuits that are disturbed in neurologic conditions, including mental illness, autism, Parkinson's disease, Alzheimer's disease, and addiction. ⁹ |
| Preventing neuroinflammation | Developing a safe and effective vaccine for the treatment of AD that will not cause an inflammatory response in the brain. ¹⁰ |
| Understanding the impact of economic concerns on older adults | Examining trends in demography, economics, health, and health care of the elderly by evaluating the effects of medical technology on costs and examining changes in survival, health, and well-being among older people over time. ¹¹ |
| | Examining the financial circumstances of older Americans, including work and retirement behavior, health and functional ability, and policies that influence individual well-being. ¹² |

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| Improving the quality of patient care | Evaluating the effectiveness of feeding tubes in the hospital setting to reduce weight loss among older adults with dementia. ¹³ |
| | Describing risk factors and long-term consequences of adverse medical events or medical injuries among older adults. ¹⁴ |
| Supporting family caregivers | Enhancing the communication skills of physicians and family members for improved decision-making and outcomes during end-of-life and/or critical care. ¹⁵ |
| Preparing the next generation of researchers | Recruiting and training doctoral-level students in health services research to prepare them for careers as independent scientists. ¹⁶ |
| | Recruiting new faculty members to enhance the capacity for transdisciplinary research on aging that examines how social context and the health care system interact to impact health outcomes for older adults. ¹⁷ |

With a sustained investment in the NIH funding base, these and other NIA-funded projects will yield breakthroughs in the screening, prevention and treatment of a host of age-associated diseases and conditions. With the FY 2011 budget, Congress has the opportunity to increase the forward momentum of NIA-funded scientists towards achieving these much-needed breakthroughs.

The Challenges and Opportunities Ahead

A key challenge is maintaining the positive momentum set into motion by Congress through the American Recovery and Reinvestment Act. Between FY 2003 and FY 2009, scientists saw a series of nominal increases and cuts that amounted to flat funding for NIH and a 12.9% reduction in constant dollars for the NIA. Six years of flat funding for the NIH took a toll on scientific progress in America – projects were sidelined, promising grants went unfunded, and countless life-saving discoveries went undiscovered. With the infusion of funding from the American Recovery and Reinvestment Act NIH researchers are regaining some of the ground lost during that time period. NIA is poised to accelerate the scientific discoveries that we as a nation are counting on America's leading researchers to achieve. With millions of Americans facing the loss of their functional abilities, their independence, and their lives to diseases like Alzheimer's Disease, Parkinson's Disease, Amyotrophic Lateral Sclerosis, and Frontotemporal Dementia, there is a pressing need for a robust and sustained investment in the work of NIH and by extension, NIA. In every community in America, health care providers depend upon NIA-funded discoveries to help their patients and caregivers lead healthier and more independent lives. In those same communities across America, parents are hoping NIA-funded discoveries will help their children have a brighter future, free from the diseases and conditions of aging that plague our nation today.

We do not yet have the knowledge needed to predict, preempt, and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have the knowledge needed about disease processes to understand how best to prevent, diagnose, and treat diseases and conditions of aging, nor do we have the knowledge needed about the complex relationships between biology, genetics, and behavioral and social factors related to aging. We do not yet have a sufficient pool of new investigators entering the field of aging research. Bold, visionary, and

sustainable investments in the NIA will make it possible to achieve measurable gains in these areas sooner rather than later.

The member groups of the Friends of the National Institute of Aging respectfully urge this Subcommittee to provide sustained support for biomedical and behavioral research by increasing NIA funding by a minimum of seven percent in Fiscal Year 2011 to correspond with the overall funding increase to NIH. NIA and the health-enhancing and life-saving biomedical, behavioral and social research it supports require bold, visionary, and sustainable funding to succeed in transforming the health of our nation. Americans depend upon the NIA to facilitate the acceleration of discoveries to prevent, treat, and potentially cure a wide range of debilitating age-related diseases and conditions. NIA-supported scientists are poised to make breakthroughs in the prevention and treatment of a host of age-associated diseases and conditions, but in order to achieve these powerful results, meaningful investments in aging research must be made now.

While the Friends of the NIA recognizes that there is enormous competition for Congressional appropriations, we believe that an increase in funding for the NIH will yield unprecedented returns in terms of accelerating the rate of basic discovery and stimulating the rapid development of interventions with the potential to offer significant public health benefits for our aging population.

Mr. Chairman, the Friends of the NIA thanks you for this opportunity to outline the challenges and opportunities that lie ahead as you consider the FY 2011 appropriations for the NIH. We would be happy to furnish additional information upon request.

Contact Information

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¹ 1 F32 AG031620-01A2 – Role of Microvascular Lesions in Alzheimer's Disease – Nozomi Nishimura (NY)

² 3 K23 NS058252-04S1 – Energy Metabolism and Brain Changes with Age and Alzheimer's Disease. – Jeffrey Burns (KS)

³ 2 R01 AG016208-10A2 – Genomic Search for Susceptibility to Alzheimer Disease – Alison Goate (MO); 1 RC2AG036528-01 – Genome Wide Associate Analysis of Alzheimer's Disease – Gerard Schellenberger (PA); 1 RC2 AG036650-01 – Genome-Wide Association Study of

Cognitive Decline Among Older African Americans – Denis A. Evans, Jill R. Murrell, and Philip De Jager (IL)

⁴ 1 RC2 NS069502 -01 – Advancing Proteomic Analysis of CSF in Nervous System Diseases. – Howard Schulman (NC); 1 RC1 AG035654-01 – LC-MS/MS Analysis of CSF and Antecedent Biomarkers of AD – David Holtzman (MO)

⁵ 1 RC1 AG036208-01 – Comparative Effectiveness of Brain Imaging and Blood Biomarkers in Alzheimer’s Disease – Orly Lazarov (IL)

⁶ 2 U01 AG015477-06A2 – Prevention of Alzheimer Dementia and Cognitive Decline – John Breitner (WA)

⁷ 1 RC1 AG035711-01 – HDAC1 Activating Compounds as Therapeutics for Neurodegenerative Disorders. Li-Huei Tsai (MA)

⁸ 2 R01 AG013743-13A1 – Spatially Oriented Database for Digital Brain Images – Edward Herskovits. (PA)

⁹ 1 RC1 NS069152-01 – A Computational Framework for Mapping Long Range Genetic Circuits – Julie R. Korenberg (contact), Tolga Tasdizen (UT)

¹⁰ 3 R01 AG20159-08S1 – Mucosal Abeta Vaccination: Modulating the Immune Response – Cynthia Lemere (MA)

¹¹ 3 P30 AG017253-10S1 – Center on the Demography and Economics of Health and Aging – Alan Garber (CA)

¹² 3 P30 AG012810-16S1 and 16S2 – NBER Center for Aging and Health Research – David A. Wise (MA)

¹³ 1 RC1 AG036418-01 – Effectiveness of Feeding Tubes Among Persons with Advanced Cognitive Impairment – Joan Teno (RI)

¹⁴ 1 R21 AG031983-01A1 – Investigation of Longitudinal Consequences of Adverse Events Among Older Adults – Mary Carter (WV)

¹⁵ 3 K23 AG032875-02S1 – A Randomized Trial To Improve Surrogate Decision-Making For Critically Ill Elders – Douglas White (CA)

¹⁶ 2 T32 AG023482-06 – Aging Health and Health Services Research Training – Vincent Mor (RI)

¹⁷ 1 P30 AG036459-01 – New Faculty Recruitment for Interdisciplinary Research on Aging – David Meltzer (IL)

Friends of NIAAA

*Testimony on behalf of the **FRIENDS OF NIAAA**
Regarding the Fiscal Year 2011 Appropriation
before the United States House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
for the **National Institute on Alcohol Abuse and Alcoholism (NIAAA)***

*Submitted by Tom Donaldson, President
National Organization on Fetal Alcohol Syndrome
(202) 785-4585, donaldson@nofas.org*

April 15, 2010

Mr. Chairman and Members of the Subcommittee:

The Friends of the National Institute on Alcohol Abuse and Alcoholism, a coalition of scientific and professional societies, patient groups, and other organizations committed to preventing and treating alcohol use disorders as well as understanding the causes and public health consequences of alcoholism and alcohol use disorders, is pleased to provide testimony in support of the NIAAA's extraordinary work. The coalition does not receive any federal funds.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is the lead agency for U.S. research on alcohol abuse, alcoholism, and other health and developmental effects of alcohol use. Its mission is to support research, and then translate and disseminate research findings to reduce alcohol-related problems. NIAAA funds 90 percent of all alcohol research in the United States. From fetal alcohol syndrome to alcohol dependence, and from liver cirrhosis to alcohol poisoning, the consequences of alcohol misuse are widespread and costly, and affect individuals of every age, ethnic background, and socioeconomic status. Drinking too early, too fast, too much, and/or too often can lead to acute and chronic consequences for the drinker as well as outcomes affecting the health and well-being of others and society-at-large.

Approximately 18 million Americans meet the criteria for a diagnosis of alcohol dependence (alcoholism) or alcohol use disorders (AUD), and 40 percent of Americans have direct family experience with alcohol use disorders or dependence. Annually, 80,000 deaths are attributable to alcohol, as are approximately one-third of all fatal car crashes, one-half of all homicides, one-third of all suicides and one-third of all hospital admissions. In fact, excessive alcohol consumption is the third leading preventable cause of death in the United States. AUDs cost the nation \$235 billion annually, nearly 80% more than the costs related to all other addictive drugs.

Because of the critical importance of alcohol research for the health and economy of our nation, we write to you today to request your support for a modest **2.7 percent increase for NIAAA** in the Fiscal 2011 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. That would bring total funding for NIAAA in Fiscal Year 2011 to

\$474,649,000. This work deserves continuing, strong support from Congress. The following is a list of key new NIAAA initiatives that could be pursued with additional investment, and a short summary of significant NIAAA accomplishments and successes.

NIAAA initiatives for FY2011:

- ❖ NIAAA will continue to support research on the mechanisms by which alcohol causes damage to, as well as pharmacologic agents that lessen alcohol's adverse effects on, the developing embryo and fetus. Resources will also be directed towards the development of biomarkers, which could be used to detect alcohol exposure in pregnant women.
- ❖ New initiatives in FY 2011 will support several broad National Institutes of Health themes, including applying genomics and other high throughput technologies to understand fundamental biology, and to uncover the causes of specific diseases, translating science into new and better treatments and putting science to work for the benefit of health care reform.
- ❖ NIAAA will support the continuing development of a screening guide for use with children and adolescents to assess for risk of alcohol use and alcohol use disorders. In addition, NIAAA is planning a new research initiative on pharmacotherapy for adolescents and young adults with severe alcohol use disorders and major co morbidities, as well as behavioral interventions that target young individuals along the continuum of alcohol related behaviors.
- ❖ In FY 2011, NIAAA will continue to promote and disseminate its web-based booklet *Rethinking Drinking*. NIAAA is planning a new initiative exploring the effects of community interventions on alcohol related outcomes in young adults. Research has demonstrated that comprehensive community interventions that typically involve multiple levels of city government, environmental policy change and community involvement, among other factors, may reduce alcohol-related problems among adolescents and young adults, including college students.
- ❖ NIAAA is planning a new initiative on developing effective pharmacological and behavioral treatments for individuals who have alcohol use disorders and co-existing other drug, psychiatric and/or physical disorders. NIAAA will also support studies aimed at risk reduction, early identification and diagnosis of harmful alcohol use and personalized treatment. Additional funds will be committed for research on the underlying mechanisms of alcohol-induced liver injury and the identification of biomarkers of alcohol-induced tissue injury. These studies are expected to reveal new therapeutic targets, inform strategies for preventing tissue injury, facilitate early diagnosis and improve the prognosis for alcohol-related liver disease.

A partial list of important NIAAA innovations:

Advancing the understanding of the mechanisms and consequences of prenatal alcohol exposure

The Friends of NIAAA commends the Institute for its research to enhance our ability for early identification of and interventions with prenatal alcohol affected children; exploring nutritional and pharmacological agents that could lessen alcohol's adverse effects on the developing embryo/fetus; and research on how alcohol disrupts normal embryonic and fetal development. Research has shown that the severity of alcohol-related effects on the developing fetus is affected by the timing and level of maternal alcohol consumption, maternal nutritional status and maternal hormones. One of the key challenges facing clinicians is the ability to recognize women who are drinking in pregnancy and the infant who has been exposed prenatally to alcohol during pregnancy. Recently there have been advances in methodologies for the measurement of non-oxidative metabolites of alcohol providing new opportunities for monitoring alcohol exposure.

Understanding the effects of alcohol use on the developing body and brain, and the interplay of development, genes and environment on adolescent alcohol use

As adolescence (ages 0-17) is the time of life during which drinking, binge drinking (drinking five or more drinks on one occasion) and heavy drinking (binge drinking five or more times in the past 30 days) all ramp up dramatically, the Friends of NIAAA is pleased that the Institute is vigorously focused on these concerns. Given that alcohol use is pervasive among adolescents and the association between early initiation and future alcohol problems, NIAAA is developing empirically based guidelines and recommendations for screening children and adolescents to identify risk for alcohol use especially for younger children; alcohol use, and alcohol use disorders. NIAAA is also supporting studies to integrate intervention for underage alcohol use into primary health care. Research has shown that during adolescence, the brain undergoes significant growth and remodeling. This finding, coupled with the results of multiple studies showing a strong association between early initiation of alcohol use and future alcohol dependence, raises concerns about alcohol's effects on the developing adolescent brain.

Specifically, the issues are whether persistent changes in neural and behavioral function result from adolescent alcohol use, and whether processes that confer adaptability of the adolescent brain to its environment also make it more vulnerable to alcohol-induced changes in structure and/or function, especially in terms of setting it up for future dependence. Complementing NIAAA's ongoing pilot studies with humans to determine if alcohol can disrupt, co-opt and/or alter normal developmental processes in the brain, NIAAA is also planning an initiative to study persistent alcohol-induced changes in the brain in animal models.

Pioneering risk assessment, universal and selective prevention, and early intervention and treatment for young adults

Given the pervasiveness of high-risk drinking and early alcohol dependence occurring among young adults, efforts to alter drinking trajectories at this stage have life-changing potential and can significantly reduce the burden of illness resulting from alcohol-related problems. Recent research has demonstrated that college-aged individuals respond well to web-based screening and self-change programs, resulting in reductions in adverse alcohol-related consequences. Making alcohol screening and brief intervention a routine procedure in primary care and other settings is a high priority of NIAAA.

Exploring pharmacologic interventions for alcohol use disorders

In addition to its role in alcohol dependence, excessive alcohol consumption can have toxic effects on virtually every organ system in the body resulting in liver and heart disease, pancreatitis, fetal abnormalities, brain damage, and an increased risk for esophageal and liver cancer. Liver disease in particular claims 37,000 lives annually, about 40% of which are due to excessive alcohol use. Currently the only treatment for liver cirrhosis – the end stage of alcoholic liver disease - is liver transplantation which is impacted by limited availability of matching organs, high medical costs, and increased risk for future health complications. Intervening early in the disease process continues to be an important priority of NIAAA, and research is moving us closer to developing medications that can slow or even reverse disease progression and/or mitigate health consequences. For example, preliminary research has shown that administration of the dietary supplement S-adenosylmethionine (SAME) may reverse disease symptoms in individuals with early stage liver disease and preempt cirrhosis. A phase 2 clinical trial testing the effects of this compound is currently underway. NIAAA and NIDDK are co-funding a project focused on developing small molecules to reverse alcoholic liver fibrosis, as well as liver damage resulting from obesity and metabolic syndromes. Animal studies evaluating prenatal and early postnatal supplementation with the nutrient choline, a molecule important to the structure and function of cell membranes, have shown reduced severity of certain behavioral and physical effects of prenatal alcohol exposure. For alcohol dependence, NIAAA is moving medications that promote abstinence and/or reduction in heavy drinking through the medications development pipeline via its early Phase 2 clinical trials program. These include trials for quetiapine, a mood stabilizing drug, completed in late FY 2009 and for levetiracetam, an antiepileptic medication, initiated in late FY 2009.

Improving the identification of mechanisms by which alcohol and its metabolites cause tissue and organ pathologies, and the development of treatment strategies for alcohol dependence tailored to specific populations and for individuals with co-existing psychiatric and medical disorders

Over the past four decades, numerous scientific advances have been made in identifying the pathologic effects of alcohol and its metabolic products on the brain, liver, heart, pancreas, and immune and endocrine systems. Recently, NIAAA has taken a systems biology approach, investigating how perturbation of one organ system by alcohol influences other organ systems, leading to a cascade of effects throughout the body. Alcohol consumption sets in motion a number of signaling processes which operate directly and indirectly on multiple systems in the body. For example, one mechanism by which alcohol negatively impacts the liver and brain is through signaling molecules released from the gut. The gut normally contains bacteria whose outer membranes consist primarily of large amounts of molecules known as lipopolysaccharides (LPS). Alcohol increases gut 'leakiness' allowing LPS to travel throughout the body, resulting in inflammation in both the brain and liver. Liver inflammation then triggers the release of cytokines, signaling molecules that promote further inflammation in the brain. Gut 'leakiness' may also be the mechanism by which alcohol disrupts immune function. Another target of alcohol may be the hypothalamic pituitary adrenal axis (HPA axis), a major part of the neuroendocrine system that regulates reactions to stress and many body processes, including digestion, the immune system, mood and emotions, sexuality, and energy storage and expenditure. Considering the human body as a complex network in which perturbations of one organ system alters interactions with other organ systems thereby affecting the functions of each,

will enable the development of treatments that address the source(s) of alcohol-induced tissue and organ damage.

The Friends of NIAAA commends the National Institute on Alcohol Abuse and Alcoholism for making significant progress in these and many other vital areas of research that are essential to the health and well-being of our nation.

Thank you, Mr. Chairman, and the Subcommittee, for your support for the National Institute on Alcohol Abuse and Alcoholism.

**Testimony Submitted to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education**

**William L. Dewey, Ph.D., President,
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April 16, 2010

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the National Institute on Drug Abuse. The Friends of the National Institute on Drug Abuse (FON) is a coalition of over 150 scientific and professional societies, patient groups, and other organizations committed to, preventing and treating substance use disorders as well as understanding their causes and society although the research agenda of the National Institute on Drug Abuse (NIDA). We are pleased to provide testimony in support of the work carried out by scholars around the country whose work is supported by NIDA. Pursuant to clause 2(g)4 of House Rule XI, the Coalition does not receive any federal funds.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our nation, estimated at over \$600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future problems.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease -- knowledge that is helping to correctly situate addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, NIDA is advancing effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends -- significant declines in a wide array of youth drug use -- over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern, such as prescription drug abuse, remain, and we support NIDA in its efforts to find successful approaches to these difficult problems.

We also want to thank the subcommittee for providing \$10.4 billion in additional spending for the National Institutes of Health, and within that total \$261,156,000 for NIDA, in the American Recovery and Reinvestment Act (ARRA). Drug abuse funding resulting from ARRA funds will speed the pace of research, provide jobs, and advance the science needed to address this devastating disease. The variety of important research - from genetic and other risk factors to neighborhood-specific prevention approaches to novel medications to treat addiction to translating effective strategies to community settings, ARRA funding will help move us toward a future when drug addiction is viewed and treated in a manner similar to other medical conditions, easing the tremendous suffering that addiction brings to individuals, communities, and our society as a whole.

Because of the critical importance of drug abuse research for the health and economy of our nation, we write to you today to request that you provide at least the President's Fiscal 2011 recommendation for the National Institute on Drug Abuse, which represents a total of \$1,094,078,000, or a 3.27 percent increase over the Fiscal 2010 level for NIDA. Recognizing that so many health research issues are inter-related, we also request that the subcommittee provide at least the President's recommendation for the National Institutes of Health, which represents a total of \$32,007,737,000, a \$1 billion or 3.22 percent increase over NIH's Fiscal 2010 level.

In addition, to highlight certain priority research areas within NIDA's portfolio, we respectfully request that you include the following language in the Committee Report accompanying the Fiscal 2011 funding recommendations for the National Institute on Drug Abuse:

Medications Development. The Committee notes that recent breakthrough scientific discoveries have vastly improved the understanding of the mechanisms of drug abuse and addiction. The Committee encourages NIDA to continue its work to harness the potential of this new knowledge to develop new, effective medications that could, either by themselves or combined with validated behavioral therapies, help alleviate the personal and social impact of this complex disease.

Focus on HIV/AIDS and Criminal Justice Populations. The committee is extremely concerned about drug abuse and HIV/AIDS in criminal justice populations, and strongly supports research efforts to empirically test the seek, test, and treat paradigm. NIDA should continue its initiative in this area, which will yield important linkages to appropriate health services and effective HIV prevention, intervention and treatment in this population.

Genetics of Addiction. The Committee understands that the causes of drug abuse and addiction are complex, with genetic, environmental, and developmental factors all contributing. The committee strongly supports NIDA's focus on understanding the various aspects and roles of genetics in addiction, and continues to recommend comprehensive future efforts focusing on identifying vulnerability genes, how environment can bring about long-term changes in gene expression (i.e., epigenomics), and how genes influence an individual's reaction to drugs and medications (i.e., pharmacogenomics).

Raising Awareness and Engaging the Medical Community in Drug Addiction Prevention and Treatment. The Committee is very pleased with NIDAMed, an initiative designed to reach out to physicians, physicians in training, and other health care professionals. The committee is especially pleased with NIDA's ongoing efforts around the Centers of Excellence for Physician Information and its Screening, Brief Intervention, and Referral to Treatment initiative. The Committee urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate NIDA-funded research findings into their clinical practices.

Tobacco Addiction The Committee recognizes that while significant declines in smoking have been achieved in recent decades, too many Americans, particularly youth, remain addicted to tobacco products. The committee applauds the recent progress of NIDA-supported researchers toward identifying genetic factors that contribute to nicotine dependence and affect the efficacy of smoking cessation treatments, and urges NIDA to continue developing much-needed evidence-based treatments, medications, and prevention strategies to combat nicotine addiction.

Prescription Drug Abuse. The Committee commends NIDA for its leadership in addressing the issue of prescription drug abuse. Data indicate a continuing high rate of nonmedical use of prescription drugs and cough syrup among teens. In fact, seven of the top 10 drugs abused by 12th graders last year were prescription or over-the-counter medications. NIDA should continue to monitor these trends and fund research designed to address related problems.

Comparative Effectiveness Research The Committee is aware of the broad focus on and importance of supporting effectiveness research within the public health sector. This type of research is essential in establishing best practices. The Committee encourages NIDA to continue its investment in this area of research so that proven models of drug abuse prevention and treatment can be further refined. These types of studies will be extremely valuable as we seek better ways to incorporate drug abuse and addiction interventions into an effectiveness-based model of medical care.

Blending Research and Practice. The Committee observes that it takes far too long for clinical research results to be implemented as part of routine patient care, and that this lag is costly for society, devastating for individuals and families, and wasteful of knowledge and investments made to improve the health and quality of people's lives. The Committee is pleased with the continued success and progress of NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN), enabling an expansion of treatment options for providers and patients and applauds NIDA for its collaborative Blending Initiative with SAMHSA, an innovative and effective effort to translate research into practice and to incorporate bidirectional feedback from multiple stakeholders to make the best drug abuse and addiction treatments available to those who need them.

Teens and Drug Abuse. The Committee commends NIDA for its educational efforts to raise awareness among teens regarding the harmful health effects associated with drugs of abuse. In addition to the highly successful Drug Facts Chat Day, the Committee supports expanded efforts toward an annual Teen Drug Awareness Week and other activities to ensure that more teens have access to this vital health information.

Focus on Military Personnel, Veterans, and Their Families. The Committee understands that NIDA has joined forces with the VA and two other NIH Institutes to support research on substance abuse and associated problems among U.S. military personnel, veterans and their families. There is a growing awareness that returning military personnel - whatever their overseas role - need help confronting a variety of war related problems including traumatic brain injury, post traumatic stress disorder, depression, anxiety, sleep disturbances, and substance abuse, including tobacco, alcohol and other drugs. Many of these problems are interconnected, and contribute to individual health and family relationship crises, yet there has been little research on how to prevent and treat the unique characteristics of wartime related substance abuse issues. The committee commends NIDA for this crucial work and asks the Institute for updated information as it becomes available.

Conclusion

The nation's investment in scientific research has changed the way people view drug abuse and addiction in this country. We now know how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies. FoN asks you to provide an appropriation of at least \$1,094,078,000 for NIDA, so that it may continue to serve the public health of all Americans and capitalize on new opportunities as science advances.

We understand that the FY 2011 budget cycle will involve setting priorities and accepting compromise. However, in the current climate, we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15-44 year olds, deserve to be prioritized accordingly. We look forward to working with you to make this a reality.

Thank you, Mr. Chairman, and the Subcommittee, for your support for the National Institute on Drug Abuse.

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Dear Members of the House Committee on Appropriations Subcommittee on Labor, Health, Human Services, Education, and Related Agencies:

I am writing to you today to express my concern and speak up against the idea of OSHA not utilizing allocated funding under Compliance Assistance for Voluntary Protection Programs (VPP) and considering a fee-based system for VPP. As an employee at a company that has achieved VPP Corporate recognition and has worked at and provides leadership to many VPP sites, I believe that this will be detrimental to the integrity of the VPP program and the culture of pro-active safety and health beyond compliance that it currently instills.

Safety and health in the workplace requires the careful balance of both enforcement methods and cooperative programs. The Voluntary Protection Programs have proven to be OSHA's premier program, adding value to workplace safety and health by requiring labor and management to work together and encouraging worksites to go beyond mere compliance. This program, which has been in existence for 26 years, now covers over 921,000 employees, giving VPP sites an average of at least 50% less injuries/illnesses than non-VPP sites. The VPP concept recognizes that compliance enforcement alone can never fully achieve the objectives of the Occupational Safety and Health Act. Good safety and health management programs that go beyond OSHA standards can protect workers more effectively than simple compliance.

I am truly concerned about the direct attack on the future of the Occupational Safety and Health Administration's (OSHA) Voluntary Protection Programs (VPP), an outstanding program that supports the Occupational Safety and Health Act of 1970. Commenting on the President's proposed FY 2011 budget, Secretary of Labor Hilda L. Solis was quoted as stating that OSHA will "*significantly reduce direct federal funding of the agency's Voluntary Protection Program (VPP)*" in favor of enforcement, despite an increase of \$14 million over FY 2010. The agency claims that this decision is a result of "*very difficult budget choices*" and "*scarce resources,*" which is not evidenced by fact. Instead, it is a policy action based on politics. I'm asking you to protect American workers by adding Appropriations language and line-item funding for VPP back into the FY2011 budget.

Congressman George Miller (D-CA), chair of the House Committee on Education and Labor, in his report to the House Budget Committee on March 4, 2010, supported the Department of Labor's (DOL) shift of funding and resources away from VPP in favor of

enforcement. He proposed to fund VPP *"through a user fee, and plans to work on establishing authority for augmenting the OSHA budget through a fee based system"*. Funding VPP through a user-fee system for recognition would take away from the independent verification of VPP sites' safety and health management system because it would lead to a direct relationship between the number of VPP sites and fees paid to the government. The over 921,000 American workers now covered by VPP have many concerns with this concept.

First, why should Industry directly fund the government to perform part of its required function under the OSH Act? Section 2 of the Occupational Safety and Health Act of 1970 - Congressional Findings and Purpose requires 13 objectives to be accomplished. Only **one** of the objectives is related to **enforcement**, however, **many more are directly related to joint labor and management efforts to establish a safe workplace** - exactly what the founders of OSHA VPP established the program to accomplish. The Voluntary Protection Programs help reinforce the reason government created OSHA. Congress and DOL taking actions to shift funding from VPP in favor of enforcement is not a return to OSHA's 'roots in enforcement,' only an Agency ignoring 12 other mandates from Congress and asking American worksites to provide that funding through a user fee-based system to pay the agency to implement many of the other requirements under the OSH Act.

One of the most important aspects of VPP, and the cornerstone of its success, is that it requires meaningful employee involvement. VPP requires that *all* employees, from hourly personnel to senior management, have a voice, participation and ownership in their safety and health programs. VPP is more than a recognition program. In the VPP, management, labor, and OSHA establish cooperative relationships at workplaces that have implemented a comprehensive safety and health management system. The VPP program requires sites to identify and address workplace hazards. This is done through the joint efforts of employers, workers and unions working together. This team goes above and beyond OSHA compliance standards and strives to continuously improve safety in the workplace to protect themselves and their coworkers. VPP is a dynamic partnership where industry takes the lead in developing and implementing higher standards. VPP sites are models of excellence that can influence best practices industry wide. Workers at VPP sites become envoys for safety and health, reaching out to other industries and employers in their local communities through mentoring and sharing of best safety practices. VPP mentoring becomes a force-multiplier that expands safety education and improvements far beyond the influence and abilities of a single OSHA compliance officer.

Second, a fee-based system would create a situation where employers can be perceived as purchasing VPP recognition that includes an exemption from routine OSHA inspections. This will have a direct affect on the integrity of the program. VPP is a comprehensive workplace safety and health management system that is built on cooperative relationships among labor, management and OSHA. If OSHA backs away

from the partnership, it will diminish the program instead of strengthening OSHA's partnership with American companies in an effort to push beyond outdated standards.

Third, fees associated with VPP may deter small businesses from participating. All groups covered by OSHA, including federal agencies are eligible to join the Voluntary Protection Programs. I have been involved with VPP and the VPPPA for 13 years – almost half the time the program has been in existence. I have experienced the success of this program while working for a small employer in a high-risk industry such as construction and for a large diversified technology, media and financial services company such as GE. Through mentoring other sites and participating on VPP evaluations through the SGE program, I have seen sites of all sizes and a variety of industries succeed in improving their safety and health management systems, ultimately saving the lives of American workers. Through VPP, best practices are shared across multiple industries.

Small businesses are collectively the largest employers in America. In recent years, smaller worksites have increased significantly within VPP, growing 11% between 2003 and 2008. In 2008, 39 percent of VPP sites are smaller worksites thanks to the mentoring efforts of current VPP employers and workers. Innovations such as the VPP Challenge Program have helped these smaller worksites keep employees safer and healthier. These smaller worksites traditionally would not see an OSHA compliance inspection or, if fined, might go out of business or need to decrease their workforce to cover an OSHA citation and associated penalties. These worksites have seen the value in a proactive safety program, such as VPP, that is saving companies and taxpayers money.

Next, charging sites for participation in VPP will have a negative cost effect on business and OSHA resources. VPP helps to free up resources for OSHA, as VPP site representatives become ambassadors for safety and health excellence. They engage in outreach and training and mentor other sites to become better – something that OSHA enforcement doesn't do. VPP sites voluntarily give in the form of funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national safety and health conferences. Additionally, when workplaces make the significant commitment to safety required by VPP, it allows OSHA to focus its enforcement resources where they are most needed.

Lastly, paying a fee reduces VPP to a government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride. While I continue to support firm and fair enforcement as a necessary tool to reach worksites that are not voluntarily improving their safety and health programs, I firmly believe that there is clear evidence that 40 years of enforcement has failed in producing the necessary culture shift that is required to achieve measurable and sustainable improvements in the protection of the American workforce and to keep American businesses competitive in a global marketplace. VPP in its 26 years of existence has

demonstrated that American worksites can undergo a culture change and achieve measurable and sustainable continuous quality improvements in safety and health that help keep the American worker safe, healthy and employed.

In 2007, OSHA evaluated the benefits of the VPP and reported that Federal Agency VPP participants, in OSHA, the Department of Energy (DOE), the Department of Defense (DOD), and the National Parks Service saved the government more than \$59 million by avoiding injuries and the private sector VPP participants saved more than \$300 million. These funds are a return on investment that are funneled into new equipment, expanding production, training, creating *'good jobs,'* keeping *'good jobs,'* and voluntarily mentoring other work sites in the community to learn the value of VPP and keeping American workers safe. That money should not be used to fund the Federal Government to perform its required obligations under the OSH Act.

The Federal Government already benefits from its involvement in VPP and from the private sector's participation in VPP, such as:

- The \$59 million saved by Federal Agency participants in VPP is money that demonstrates fiscal responsibility and cost avoidance and allows for the reallocation of resources to the mission of the Agency.
- The U.S. Department of Labor's Safety, Health, and Return-to-Employment (SHARE) initiative was launched in 2004 to help the Federal Government in reducing injury and illness cases and lost production day rates, and to substantially improve timely filing of injury and illness notices. Agencies that adopted VPP achieved greater and sustainable improved performance in the SHARE initiative and want to expand the VPP throughout their operations.
- The DOD, with 31 VPP sites, has seen a substantial return on investment by adopting VPP in terms of reduced injuries and illnesses and a strong improvement in maintaining mission-readiness.
- OSHA also directly benefits by reducing employee injuries and illnesses at three of its Regional Field Offices that are VPP.
- Additionally, when workplaces make the significant commitment to safety and health required by VPP, it allows OSHA to focus its resources of enforcement where they are most needed – on those companies that *"don't get it"* – as stated by the Secretary of Labor.

Congress and the Department of Labor Occupational Safety & Health Administration's idea to shift funding from VPP in favor of enforcement is not a return to OSHA's "roots in enforcement," it is only an Agency ignoring 12 other mandates from Congress and asking American's worksites to provide that funding through a user fee-based system to pay the agency to implement all the requirements under the OSH Act. OSHA was provided a budget increase in 2011; however it seems to be making a political decision to cut VPP funding. It is a mistake for our government to redirect funding and resources away from a great program like VPP. Instead OSHA should concentrate on maintaining the integrity of the program by following through on recommendations in

the GAO report and listening to its stakeholders regarding ways to better utilize VPP member site resources such as SGEs.

There are lots of tools that OSHA has, however, when government continues to return to only one tool in OSHA's toolbox to achieve a safe workplace – and that tool is enforcement – we will never achieve, as a nation, the necessary culture, mindset and attributes necessary to protect our most valued asset – the American worker. VPP is a win-win-win situation for employers, employees and OSHA. Our workforce needs to continue to work together to ensure that we keep jobs in this country.

I urge you to take a stand in support of the American workforce and speak out against the idea of a fee-based Voluntary Protection Programs and to ensure the continued success of OSHA's VPP as a cooperative program by reinstating direct and continued funding in the DOL budget. Highly successful cooperative programs like VPP should be funded and expanded if OSHA is to assist American businesses in achieving the necessary cultural change required to maintain and protect American workers, which is a proven method that supports OSHA's mission. I ask that you stand behind the American workers and companies that look to cooperate with government to prevent workplace injuries by providing full funding in the DOL budget for VPP and include specific Appropriations language to restore and direct the Agency to fund, resource load and conduct VPP assistance, application evaluations, onsite re-approvals and new onsite evaluations to the levels equal to or greater than those achieved in 2005. The nearly 1 million workers striving to get all of America's workplaces up to VPP standards and attain performance levels that "*go above and beyond OSHA requirements*" will thank you.

Sincerely,

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Harlem United Community AIDS Center, Inc.
Written Testimony to the House Labor-Health and Human Services
Appropriations Subcommittee
Regarding FY 2011 CDC HIV/AIDS Related Funding
Submitted by: Patrick McGovern, President & CEO,
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April 16, 2010

Harlem United Overview

Harlem United Community AIDS Center, Inc. (Harlem United) is a community-based, non-profit organization providing comprehensive, integrated care to individuals and families living with HIV/AIDS in Upper Manhattan area of New York City and its nearby boroughs.

Harlem United provides a full range of medical, social, and supportive services to people living with HIV/AIDS whose diagnoses are often complicated by addiction, mental illness, and homelessness. Harlem United utilizes a comprehensive model of care that includes HIV testing; treatment and education; primary medical care; substance use counseling; mental health services; and an array of expressive therapies. Each year we touch the lives of more than 6,000 people through our services and myriad locations, including two AIDS Adult Day Health Care centers. At these centers, patients receive medication management, health care monitoring, case management, substance abuse services, nutritional services, and health education. We are proud that we deliver evidence-based, outcome-driven, comprehensive, medically-endorsed care in a cost-effective and supportive setting.

Harlem United is very concerned about increasing HIV incidence among men who have sex with men (MSM) of all races and ethnicities. Harlem United's Black Men's Initiative endeavors to reduce rates of HIV infection and transmission of sexually transmitted infections (STIs) among young Black and Latino MSM in New York City. Our Education and Training Department works with populations and individuals at increased risk for HIV infection, such as MSM, to increase knowledge and skills to prevent HIV transmission and improve HIV-related health outcomes. Our programs include evidence-based HIV prevention interventions, comprehensive risk-reduction counseling, confidential HIV rapid testing and STI screenings, primary care, mental health, and supportive housing services many of which specialize in mobilizing effective responses for Black and Latino MSM.

HIV/AIDS and MSM

MSM account for nearly half of the more than one million people living with HIV in the United States and half of all new HIV infections in the United States each year. While the Centers for Disease Control and Prevention (CDC) estimates that MSM account for just four percent of the U.S. male population aged 13 and older, the rate of new HIV diagnoses among MSM in the U.S. is more than 44 times that of other men and more than 40 times HIV diagnoses among women. MSM is the only risk group in the U.S. in which new HIV infections are increasing.¹

¹ "CDC Fact Sheet: HIV and AIDS among Gay and Bisexual Men," Centers for Disease Control and Prevention (March 2010). Available at <http://www.cdc.gov/nchstp/newsroom/docs/FastFacts-MSM-FINAL508COMP.pdf>.

*Harlem United Community AIDS Center, Inc.
FY 2011 Written Testimony Submitted to the
House LHHS Appropriations Subcommittee
April 16, 2010*

As the CDC's Fiscal Year (FY) 2011 Congressional Justification noted, MSM of all races/ethnicities are at increased risk, but substantial racial/ethnic disparities do exist among MSM, with Black and Hispanic MSM bearing the greatest burden of the disease. The most alarming HIV infection increases are occurring among MSM ages 13 – 29 and 45 and older.² Despite having lower infection rates than older MSM, younger MSM are more likely to have an undiagnosed HIV infection. HIV infection among MSM is facilitated by a number of factors including STIs, substance use, and community fatigue with HIV prevention messages. CDC should work with community leaders to inform methodology for communicating about HIV burden in MSM communities that encourages, rather than discourages, greater adoption of effective HIV prevention strategies.

According to the CDC, recent increases in syphilis have largely been seen among MSM and syphilis is associated with a two-to-five fold increased risk of HIV. Higher rates of gonorrhea, which also facilitates HIV acquisition and transmission, have been documented among MSM who are HIV-infected. Thus, more needs to be done to address STIs and HIV for MSM given their elevated risk for infection. CDC data published in 2005 suggest that as few as one in five MSM received individual or group-level HIV prevention interventions in the prior year.³

CDC Program for MSM

In the FY 2011 budget, the President has requested \$27 million for CDC to undertake targeted HIV and STI prevention efforts for MSM. We understand this initiative will build on an effort begun in 2008, when the CDC provided \$4 million in supplemental funding to 51 health departments to re-assess and strengthen their plans to address HIV among MSM in their jurisdictions. Harlem United is pleased that the CDC will expand this focused initiative to prevent HIV through holistic and integrated approaches to protect the health of gay, bisexual, and other MSM. We applaud this multi-year effort to prevent new HIV infections, reduce the acquisition of STIs, and address substance abuse. Harlem United hopes that additional resources will be directed to this effort as they are identified.

Studies show that the majority of individuals who are aware of their HIV-positive diagnosis proactively make changes to their behavior to prevent further spread of HIV. Increased access to routine HIV testing, irrespective of risk, is a key policy priority for Harlem United; as such, we hope that the expanded MSM effort will complement the 2010 HIV Expanded Testing Initiative focused on MSM.

² "Fiscal Year 2011 Centers for Disease Control and Prevention Justification of Estimates for Appropriations Committees," Department of Health and Human Services, 74. Available at http://cdc.gov/fmo/topic/Budget%20Information/appropriations_budget_form_pdf/FY2011_CDC_CJ_Final.pdf.

³ "Fiscal Year 2011 Centers for Disease Control and Prevention Justification of Estimates for Appropriations Committees," 74.

*Harlem United Community AIDS Center, Inc.
FY 2011 Written Testimony Submitted to the
House LHHS Appropriations Subcommittee
April 16, 2010*

We anticipate that the additional resources requested for FY 2011 by the President will expand HIV testing and prevention services to more MSM who need them, improve monitoring for co-infections among MSM and HIV-infected persons, and support the development and refinement of intervention services specifically for MSM. Based upon the racial and ethnic burden of HIV/AIDS among Hispanic and Black MSM and Harlem United's strong commitment to serve this population, we are pleased that the CDC efforts will be focused on these populations.

Social determinants are an essential component to determining HIV vulnerability among MSM. Effective HIV prevention strategies must be mobilized simultaneously on an individual and community-level to successfully reduce HIV vulnerability and infections. We encourage CDC to utilize these new resources to promulgate a full continuum of HIV prevention interventions which provide MSM with an array of strategies that will best enable them to protect their sexual in the various ways they might experience HIV-risk in their lives. Harlem United maintains that HIV prevention among MSM should include the following initiatives:

- Increase capacity among existing community-based organizations whose primary focus is HIV prevention among MSM, particularly MSM of color, or have programs which focus primarily on HIV prevention among MSM;
- Targeted social and sexual network based HIV testing approaches, inclusive of internet-based outreach;
- Peer-driven linkage to care initiatives that strive to connect newly diagnosed and lost-to-care HIV-positive MSM to high-quality and affordable health care; and
- Culturally-competent social marketing campaigns which reach beyond HIV testing and condom use to educate MSM communities about strategies to protect themselves from HIV reflective of existing community risk behaviors.

Finally, given the alarming disparity of HIV and syphilis incidence among MSM, we also urge the CDC to assemble an MSM advisory group that would provide guidance to decision-making officials in the Division of HIV/AIDS Prevention on barriers to implementation and best practices to be replicated. Further, this advisory group would work with CDC to integrate HIV and STI prevention and screening programs in clinical and community-based settings.

We urge Congress to fulfill the President's request of \$27 million for the CDC's MSM HIV and STI program and ensure that available resources reach communities and populations who need them most.

Conclusion

We very much appreciate the opportunity to provide written testimony in support of our nation's efforts to prevent HIV/AIDS among gay, bisexual, and other MSM at the CDC. While President Obama's budget certainly reflects his commitment to the domestic fight against HIV/AIDS, any increase in funding Congress provides to the CDC program aimed at preventing HIV/AIDS and STIs among MSM would be greatly appreciated and would help us further our efforts to reverse

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the ever growing HIV epidemic in Harlem, other New York neighborhoods, and across the nation.

Harlem United is a member of the Federal AIDS Policy Partnership and joins in the coalition's funding requests with respect to domestic HIV/AIDS prevention funding and its call for increased funding for the Ryan White Care Act programs.

Harlem United stands ready to be a resource for the Subcommittee and its staff with respect to HIV/AIDS prevention, the care and treatment of individuals living with HIV/AIDS, and the provision of supportive services for individuals living with HIV/AIDS and the homeless.

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Statement by

Paul H. Phaneuf

Trustee

Helen Keller International

Subcommittee on Labor, Health and Human Services,

Education and Related Agencies

Committee on Appropriations

U.S. House of Representatives

April 16, 2010

Paul H. Phaneuf is testifying on behalf of ChildSight®, the domestic program of Helen Keller International that provides free, in-school vision screenings and prescription eyeglasses for children living in underserved communities in the U.S.

Mr. Chairman, thank you for this opportunity to provide testimony to the Subcommittee on behalf of Helen Keller International's ChildSight® program. My name is Paul H. Phaneuf and I serve as a member of HKI's Board of Trustees. I am requesting that this Subcommittee recommends \$1.5 million in fiscal year 2011 funding be provided through the United States Department of Education to support HKI's ChildSight® program. It is HKI's hope that with the continued support of the Department of Education and private donors we can deliver vision screenings and eyeglasses to thousands of economically disadvantaged children who have extremely limited access to immediate and affordable vision care.

CHILDSIGHT®

Established in 1994, ChildSight® tackles the common problem of refractive error among children and adolescent students in underserved communities in the U.S. Refractive error, also known as near-sightedness, far-sightedness and astigmatism, occurs in approximately 25% of all U.S. children between the ages of 10 and 15. It is easily treated with a pair of corrective eyeglasses. Yet millions of students do not get the care they need due to limited access to vision screening and the prohibitive cost of a pair of prescription eyeglasses. ChildSight® targets these communities and serves at-risk children by providing free screening, free eyeglasses and free follow-up care so that students can focus in the classroom in order to achieve their potential for future academic and vocational success.

ChildSight® is distinguished by its high clinical standards and its efforts to educate children and their families about the importance of corrected vision and the availability of related healthcare resources in their community. The hallmark of the program is to provide prescription eyeglasses at the school site. The service provided by ChildSight® is prompt, convenient, and seeks to overcome the economic, social and transportation barriers that prevent many children from low-income families from obtaining the vision care they need. ChildSight® provides direct access to vision screening and refraction by a licensed optometrist, who prescribes the necessary lenses for each child. Students who need eyeglasses receive them – on-site and free of charge – typically within one week.

But ChildSight® goes even one step further. Students identified with potentially severe eye conditions beyond basic refractive error are referred to our partnering ophthalmologists for a full eye exam and follow-up treatment as needed, at no additional cost. This final step ensures that children who need further assessment and care will be able to receive it, regardless of their family's ability to pay.

With support from this Subcommittee, the Department of Education and private donations, ChildSight® has now screened over 1.3 million children in over 500 schools nationwide and has delivered free prescription eyeglasses to more than 159,000 students since 1994.

The children served by ChildSight® come from economically disadvantaged families who have extremely limited access to basic health or vision care. We select the schools we serve based on demonstrated need, using criteria such as high student poverty levels (as determined by enrollment in free or reduced-price lunch programs), a history of high eyeglass distribution rates (if ChildSight® has previously serviced the school), and whether the school receives government assistance. All of our services are provided on-site and at no expense to the child's family.

We have seen the positive results of the ChildSight® program. Teachers we have surveyed throughout the country report that a majority of students who had their vision corrected with ChildSight® eyeglasses exhibited:

- significant improvement in the completion of schoolwork and homework;
- increased class participation and a reduction in disruptive behavior; and
- a dramatic improvement in grades, self-confidence and self-perception.

CHILDREN WITH VISUAL NEEDS

The mission of ChildSight® is to improve the vision and academic potential of economically disadvantaged children. Research has established a clear link between vision and learning. Most learning platforms – books, computer screens, blackboards and classroom presentations – require clear vision in order for a child to interact, assimilate information, and respond.

Yet in thousands of classrooms, millions of children are unable to make the most of their education, simply because they cannot see well. Unable to focus on lessons or homework, they are at risk of falling behind, tuning out, acting out or even dropping out. While there are myriad causes of poor academic performance, one potential factor is impaired vision. This is especially tragic since most cases of poor vision are due to refractive error and are easily corrected.

The data collected by ChildSight® over 16 years of service confirms that an average of one in every four children between the ages of 10 and 15 fail standard vision screenings as a result of refractive error. If not detected and treated promptly, refractive error and other eye conditions can lead to long-term visual deficiencies and developmental problems. Students must have clear, healthy eyesight in order to fully focus on schoolwork and classroom lessons, or the opportunity to gain a valuable education is severely diminished. Later in life, adults whose visual impairment denied them the chance to gain core academic skills are at a disadvantage in seeking employment and achieving economic independence.

In most cases, the solution is simple: the provision of correctly prescribed eyeglasses. However, millions of children in the U.S. suffer from uncorrected vision problems due to various social, economic and transportation barriers, as well as inconsistent or inadequate detection and treatment under existing school health programs.

ChildSight® bridges this gap by going directly into the schools to conduct vision screenings, to identify children with refractive error, and to provide them with prescription eyeglasses to correct this error, all free of charge. In so doing, ChildSight® works to “bring education into focus™” for children who would otherwise be left with untreated vision problems – and lost opportunities.

AREAS SERVED BY CHILDSIGHT®

Helen Keller International established ChildSight® in New York City in 1994. Today the program serves children in over 25 urban and rural communities in seven states: California, Connecticut, New Jersey, New Mexico, New York, Ohio, and Texas.

Support from the Department of Education has played a key role in the success and growth

of ChildSight® , including the program's rapid geographic expansion achieved from 2000 to 2005. For example, in 2004, HKI established ChildSight® in Gallup, New Mexico, to help ameliorate the burden of rural poverty and the dearth of accessible health care services for many residents living in and around the Navajo Reservation. Since then, ChildSight® has screened over 25,000 students within Gallup-McKinley County public schools and Bureau of Indian Affairs schools, and has delivered over 7,000 pairs of free prescription eyeglasses to those students in need.

ChildSight® New Mexico continues to witness a significant need for eyeglasses among the students we screen, due in large part to extremely limited access to health care professionals, widening economic disparities, and the prevalence of astigmatism among many Native American children.

PROGRAM INNOVATION

HKI also continually seeks to improve and expand the ChildSight® program through innovation. In 2005, ChildSight® began screening pre-school children in New York City. Modeled after the original ChildSight® program, which targets children between ages 10 and 15, the ChildSight® Pre-K program addresses the vision care needs of underserved children between ages 3 and 4, the age range when amblyopia (also known as "lazy eye") can be strategically identified and treated. Since 2005, ChildSight® Pre-K has now provided sight-saving services to over 16,000 pre-school children in New York City, most of whom had never received any eye health services before.

In the 2009-2010 school year, ChildSight® began serving adolescents within alternative GED programs in New York City. The initial success of this pilot prompted HKI to consider launching a similar initiative in other ChildSight® sites, as a means to fulfill an unmet need among adolescents who have become derailed from the traditional school setting.

PUBLIC/PRIVATE UNDERTAKING

ChildSight® is truly a public/private endeavor. The program's success is due in large part to the dedication and commitment of the many physicians, educators, community activists and business people at each of our local sites. Along with their support and the contributions of foundations and corporations, we continue to seek the institutionalization and long-term sustainability of our programs. The endorsement and support by the Department of Education have played an integral role in our ability to leverage committed support from the private sector. ChildSight® has received significant long-term funding from several foundations including the Eisner Foundation, Community Foundation for Greater New Haven, Daniels Fund, New York Community Trust, Lavelle Fund for the Blind, Reader's Digest Partners for Sight Foundation, Victoria Foundation, Rose Hills Foundation, and Mt. Sinai Health Care Foundation.

Local health care professionals at each of our sites are members of the ChildSight® team, and more than 35 optometrists, pediatric ophthalmologists and opticians help us meet the vision care needs of the students we serve. ChildSight® contracts with over 20 ophthalmic clinics and seven optical shops nationwide, all selected for their strong professional credentials. Services of all these community professionals are either donated or provided at a reduced, reasonable rate.

SOLVING THE PROBLEM

I ask that this Subcommittee recognize the importance of children's eye health, and support our concern that much more needs to be accomplished to address this problem. I also ask you to consider the reality that children in many areas of urban and rural poverty are missing the chance to be helped because of limited funding. Children who need eyeglasses must receive them while they are still in school, so that they can make full use of their educational opportunities.

Refractive error affects a child's quality of life, often resulting in lost education and reduced future employment opportunities, lower productivity, emotional frustration and social exclusion. Among economically disadvantaged, predominantly minority, public school students in our nation, the inability to learn due to poor vision is widespread, and largely unaddressed. This is especially unfortunate since this is a result of an easily treatable but overlooked visual deficiency. ChildSight® engages students, parents, teachers, local healthcare providers and district and community administrators to address this vital health concern and "bring education into focus™" for underprivileged children.

HKI has the credentials and the tools to strategically address this problem. But we cannot do it alone. Support for ChildSight® is needed more now than ever as demand for our services rises in lockstep with economic disparities and increased difficulty in accessing adequate health care.

In closing, I ask this Subcommittee to recommend that at least \$1.5 million from the Department of Education's 2011 fiscal year budget be used to support ChildSight® in its current locations and to expand its current services to other regions of the country. These Department of Education funds will support our ongoing programs and will enable us to screen the vision of approximately 100,000 additional economically disadvantaged children during the 2011-2012 school year.

I hope the Subcommittee will consider this request favorably, as ChildSight® provides an invaluable – and often life-changing – service to local youth, and does so in a pragmatic and cost-effective manner.

Thank you, Mr. Chairman. Your attention and consideration are greatly appreciated, and I close with the wise words of our founding board member, Helen Keller: *A lone we can do so little, together we can do so much.*



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STATEMENT
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ON BEHALF OF THE
HEPATITIS B FOUNDATION
DOYLESTOWN, PA

PRESENTED
TO THE
UNITED STATES HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS

SUBCOMMITTEE ON LABOR,
HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES

April 16, 2010

This testimony is being provided to highlight the urgent need to address the public health challenges of chronic hepatitis B by strengthening programs at the Centers for Disease Control and Prevention, and the National Institutes of Health.

Mr. Chairman, my name is Dr. Timothy Block, and I am the President and Co-Founder of the Hepatitis B Foundation and its research institute, the Institute for Hepatitis and Virus Research. I also serve as the President of the Pennsylvania Biotechnology Center and am a professor at Drexel University College of Medicine. My wife Joan, and I, and another couple, Paul and Janine Witte, from Pennsylvania started the Hepatitis B Foundation almost 20 years ago to find a cure for this serious chronic liver disease and provide information and support to those affected.

Thank you for giving the Hepatitis B Foundation (HBF) the opportunity to provide testimony to the Subcommittee as you begin to consider funding priorities for Fiscal Year (FY) 2011. We are grateful to the Members of this Subcommittee for their interest, and particularly Congressman Honda, who has provided consistent and strong leadership for efforts to control and find cures for hepatitis B. We are also thankful to Subcommittee member Jesse Jackson, Jr. for his tireless efforts to address the issue of racial disparities and note that Hepatitis B is the largest single issue of racial health disparity for Asian and Pacific Islander Americans. Finally, we remember fondly former Subcommittee Member Dan Miller who championed this cause and helped increase the CDC's Division of Viral Hepatitis to \$25 million in FY 2003. Sadly, the Division is now funded at only \$19 million even though the challenges only grow.

Today, the HBF is the only national nonprofit organization solely dedicated to finding a cure and improving the lives of those affected by hepatitis B worldwide through research, education and patient advocacy. Our scientists focus on drug discovery for hepatitis B and liver cancer, and early detection markers for liver cancer. HBF staff manages a comprehensive website which receives almost one million visitors each year, a national patient conference and outreach services. HBF public health professionals conduct research initiatives to advance our mission.

The hepatitis B virus (HBV) is the world's major cause of liver cancer – and while other cancers are declining, liver cancer is the fastest growing in incidence in the U.S. Without intervention, as many as 100 million worldwide will die from a HBV-related liver disease, most notably liver cancer. In the U.S., up to 2 million Americans have been chronically infected and more than 5,000 people die each year from complications due to HBV.

HBV is 100 times more infectious than the HIV/AIDS virus. Yet, hepatitis B can be prevented with a safe and effective vaccine. Unfortunately, for those who are chronically infected with HBV, the vaccine is too late. There are, however, promising new treatments for HBV. We are getting close to solutions but lack of sustained support for public health measures and scientific research is threatening progress. The growing incidence of liver cancer, while most other cancer rates are on the decline, represents examples of serious shortcomings in our system. In the U.S., 20,000 babies are born to mothers infected with HBV each year, and as many as 1,200 newborns will be chronically infected with the hepatitis B virus. More needs to be done to prevent new infections.

INSTITUTE OF MEDICINE REPORT

In January of this year, the Institute of Medicine issued a report titled *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*. This report outlined a national strategy for prevention and control of hepatitis B and C. The report concludes that the current approach to the prevention and control of viral hepatitis is not working and unless further action is taken thousands more Americans will die each year from liver cancer, or liver disease associated with these preventable diseases. In response to this monumental report, the Department of Health and Human Services Office of the Secretary has convened an inter-departmental task-force to address the public health challenge of viral hepatitis. The Hepatitis B Foundation is very supportive of the Task Force and is hopeful that their recommendations will result in actions to address the chronic underfunding of viral hepatitis prevention programs within the Department.

Mr. Chairman, as you know the two federal agencies that are critical to the effort to help people concerned with hepatitis B are: the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health CDC (NIH).

THE CENTERS FOR DISEASE CONTROL

CDC's Division of Viral Hepatitis (DVH), the centerpiece of the federal response to controlling, reducing and preventing the suffering and deaths resulting from viral hepatitis, is chronically underfunded. DVH is included in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the CDC, and is responsible for the prevention and control of viral hepatitis. DVH is currently funded at \$19.3 million, \$6 million less than its funding level in FY 2003, which does not allow for the provision of core prevention services. The HBF joins the hepatitis community and urges a FY 2011 funding level for the Division of Viral Hepatitis of \$50 million.

The responsibility for addressing the problem of hepatitis should not lie solely with the Division. In view of the preventable nature of these diseases, the Hepatitis B Foundation feels that the National Center for Chronic Disease Prevention should also include a targeted effort focused on the prevention of chronic viral hepatitis which adversely impacts 5 million Americans. We urge that the Committee include \$2 million in the National Center for Chronic Disease Prevention to initiate a focused program on chronic viral hepatitis.

Furthermore, there are 400 million people chronically infected with hepatitis B worldwide, with more than 120 million of these individuals in China. While hepatitis B transmission requires direct exposure to infected blood, worldwide misinformation about the disease has fueled inappropriate discrimination against individuals with this vaccine-preventable bloodborne and treatable disease. HBF urges the Committee to instruct the CDC to initiate global programs to increase the rate of vaccination, reduce mother-child transmission and promote educational programs to prevent the disease and to reduce discrimination targeted against individuals with the

disease.

THE NATIONAL INSITUATES OF HEALTH

We depend upon the NIH to fund research that will lead to new and more effective interventions to treat people with hepatitis B and liver cancer. The Hepatitis B Foundation joins with the Ad Hoc Group for Biomedical Research and requests a funding level of \$35 billion for the National Institutes of Health in FY 2011.

We thank the Committee for their continued investment in NIH in FY 2010. Sustaining progress in medical research is essential to the twin national priorities of smarter health care and economic revitalization. With additional investment, the nation can seize the unique opportunity to build on the tremendous momentum emerging from the strategic investment in NIH made through the 2009 American Recovery and Reinvestment Act (ARRA). NIH invested those funds in a range of potentially revolutionary new avenues of research that will lead to new early screenings and new treatments for disease.

In FY 2009, NIH spent approximately \$57 million on hepatitis B funding overall (ARRA and non-ARRA funds), and estimates that in FY 2010 \$54 million will be spent. An additional \$40 million per year could make transformational advances in research leading to better treatments for HBV. The HBF recommends that an additional \$40 million be allocated for HBV research in FY 2010 and that overall NIH funding total \$35 billion.

The current leadership of the NIH has performed admirably with the limited resources they are provided; however, more is needed. While a number of cancers have achieved five-year survival rates of over 80 percent and the average five-year survival rate for all cancers has increased from 50 percent in 1971 to 66 percent, significant challenges still remain for other types of cancers, particularly the most deadly forms of cancer. In fact, nearly half of the 562,340 cancer deaths in 2009 were caused by eight forms of cancer with five-year relative survival rates of less than 50 percent: ovary (45.5%), brain (35.0%), myeloma (34.9%), stomach (24.7%), esophagus (15.8%), lung (15.2%), liver (11.7%), and pancreas (5.1%). It is no coincidence that cancers with significantly better five year survival rates, such as breast, prostate, colon, testicular, and chronic myelogenous leukemia, also have early detection tools, and in many cases, several effective treatment options thanks to research programs championed and supported by Congress. By contrast, research into the cancers with the lowest five-year survival rates has been relatively under-funded, and as a result, these cancers have no early detection or treatment tools.

The Hepatitis B Foundation requests that the establishment of a targeted cancers program at the NCI for the high mortality cancers. It should include a strategic plan for progress, an annual report from NCI to Congress, and a new grant program specifically focused on the deadly cancers. Additionally, the Hepatitis B Foundation urges a stronger focus on liver cancer and urges the funding of a series of Specialized Programs of Research Excellence (SPoREs) focused

on liver cancer. While SPORes currently exist for every other major cancer, none currently exist that are focused on liver cancer.

SUMMARY AND CONCLUSION

While the HBF recognizes the demands on our nation's resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify higher funding levels for the CDC's Division of Viral Hepatitis and the National Institutes of Health.

Significant progress has been made in developing better treatments and cures for the diseases that affect humankind due to your leadership and the leadership of your colleagues on this Subcommittee. Significant progress has also similarly been made in the fight against hepatitis B. In conclusion, we specifically request the following for FY 2011:

- Fund the CDC's Division of Viral Hepatitis at \$50 million;
- \$2 million in the National Center for Chronic Disease Prevention to initiate a focused program on chronic viral hepatitis;
- Initiate global programs at the CDC to increase the rate of vaccination, reduce mother-child transmission and promote educational programs to prevent the disease and to reduce discrimination targeted against individuals with the disease;
- Provide \$35 billion for the National Institutes of Health, including a \$40 million increase per year for hepatitis B research;
- Establish a targeted cancers program at the NCI; and
- Fund a series of Specialized Programs of Research Excellence (SPORes) focused on liver cancer at the NCI.

The Hepatitis B Foundation appreciates the opportunity to provide testimony to you on behalf of our constituents and yours.

Thank you.



Written testimony by Evelyn McKnight, AuD
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Submitted on April 16, 2010 to the US House Subcommittee on Labor, Health and Human Services, Education and Related Agencies
House Appropriations Committee
H-218 US Capitol
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Addressing the Centers for Disease Control & Prevention (CDC) and Department of Health & Human Services (HHS)

Mr. Chairman and Members of the Subcommittee:

As President and Co-Founder of Hepatitis Outbreaks National Organization for Reform (HONOREform), I want to take this opportunity to thank you for the leadership role this Subcommittee has played on healthcare acquired infections (HAIs). HONOREform is a non-profit foundation that advances the lessons learned in hepatitis outbreaks and seeks to prevent future healthcare-associated hepatitis epidemics through education and policy reform.

The Centers for Disease Control and Prevention (CDC) estimates there are 1.7 million infections resulting in approximately 99,000 deaths annually in the United States, making HAIs the fourth leading cause of death. Beyond the human toll, there is an enormous financial burden to our healthcare system.

We are deeply concerned with the rise in the number of disease outbreaks related to the reuse of syringes and misuse of multidose vials in the outpatient setting. In the January 2009 edition of the *Annals of Internal Medicine*, an article by the CDC, revealed the occurrence of 33 outbreaks of viral hepatitis in healthcare settings over the last decade. All of these documented outbreaks occurred in non-hospital settings and involved failure on the part of healthcare providers to adhere to basic infection control practices, most notably by reusing syringes and other equipment intended for single use.

I am a victim of what was the largest single source outbreak of Hepatitis C in U.S. history, until 2008 when an outbreak that potentially exposed over 63,000 patients to hepatitis C occurred in Las Vegas, Nevada. In 2001, I contracted hepatitis C through an oncology clinic (non-hospital setting), in Fremont,

Nebraska as I was fighting to survive breast cancer for the second time. 98 other patients from the oncology clinic became infected with hepatitis C. The nurse would reuse the syringe for port flushes, which would then contaminated a 500cc saline bag. The saline bag was used for other patients, which in turn became the source of infection for multiple cancer patients. This improper practice was repeated on a regular basis over a 2-year period.

I utilized my malpractice settlement to establish HONORreform in 2007 to put an end to these completely preventable outbreaks. Over 100,000 patients seeking healthcare and treatment have received letters notifying them of potential exposure to hepatitis and HIV due to improper injection practices in the last ten years. In April 2009, two outbreaks in New Jersey, a cancer clinic and hospital, and an outbreak at a South Dakota-outpatient urology clinic, conducted large patient notifications which further illustrates that this problem requires immediate action to protect the citizens that are accessing our healthcare system each day.

Moreover, these hepatitis outbreaks are entirely preventable when healthcare providers adhere to proper infection control procedures. A 2002 study by the American Association of Nurse Anesthetists (AANA) found that 1% of practitioners felt it was acceptable to reuse a syringe for multiple patients and over 30% of healthcare providers believed it was acceptable to reuse a syringe on the same patient if the needle is changed.

Mr. Chairman, beyond the significant risk posed to the physical health of patients, even the receipt of a notification of potential exposure can cause significant mental anguish and lead to an even greater danger – a loss of faith in the medical system by the public. Victims feel that they have been personally violated and betrayed by those to whom they entrusted their health. We, as a nation, cannot afford to ignore the issue and hope it goes away.

Through its foundation, HONORreform has joined forces with the Accreditation Association for Ambulatory Health Care (AAAHC), American Association of Nurse Anesthetists (AANA), Association for Professionals in Infection Control and Epidemiology (APIC), Ambulatory Surgery Foundation (ASF), Becton, Dickinson and Company (BD), CDC, CDC Foundation, Nebraska Medical Association (NMA), and the Nevada State Medical Association (NSMA), to establish the One & One Campaign. The One & Only Campaign, which is currently being piloted in New York and Nevada, is an effort aimed at reeducating healthcare providers that syringes and other medical equipment must not be reused and empowering patients to ask the right questions when seeking healthcare. If patients are knowledgeable about injection safety, they will be empowered to speak up in their provider's office to ask if they are getting *"One Needle, One Syringe, and Only One Time"*.

Each of these requests will have a profound impact on all patients and consumers. They are aimed at reducing the knowledge gap for providers, empowering patients, tracking HAIs to limit the spread of disease, and improving the quality and standards of care in our nation's ambulatory care facilities. By focusing on prevention, this committee can realize savings for healthcare systems and promote increased patient safety for all Americans.

Mr. Chairman, we respectfully request that the Subcommittee continue supporting prevention efforts at CDC, and HHS to help prevent future hepatitis and HIV outbreaks through the following two FY 2011 appropriations requests:

1) Supporting CDC's Division of Healthcare Quality and Promotion

HONORreform requests \$26 million for Centers for Disease Control and Prevention's (CDC) Division of Healthcare Quality and Promotion to address outbreaks and promote innovative ways to adhere to injection safety and infection control guidelines.

The CDC provides national leadership in surveillance, outbreak investigations, laboratory research, and prevention of healthcare-associated infections. The transition of healthcare delivery from primarily acute care hospitals to other healthcare settings (e.g., home care, ambulatory care, free-standing specialty care sites, long-term care) requires that common principles of infection control practice be applied to the spectrum of healthcare delivery settings. In light of the recent healthcare-associated transmissions of HCV in Denver, Colorado, Las Vegas, Nebraska, North Carolina, New York City, Long Island, and Grand Rapids, Michigan, the CDC needs additional resources to use the knowledge gained through these activities to detect infections and develop new strategies to prevent healthcare-associated transmission of blood borne pathogens.

Provider Education & Awareness (\$5 million)

Funds to develop safe practice tools for additional inpatient and outpatient healthcare settings in conjunction with key partners and stakeholders. This will include training tools to be used by professional organizations and accreditation and licensing groups to increase adherence to recommendations. Funds will assist in dissemination and use of tools to aid in implementing State HAI Action Plans. Funds to expand the One & Only injection safety education and awareness campaign, provide educational materials to all 50 states through state health departments' HAI coordinators implement a national media launch to promote awareness of the One & Only Campaign in collaboration with the Safe Injection Practices Coalition and State health departments; and evaluate the impact of the Campaign. Funds to expand implementation of CMS surveys of injection safety practices in ambulatory surgical centers to all outpatient settings.

Engineering and Innovation (\$7 million)

Funds to support the CDC in promoting private-sector and academic health care solutions to injection safety and infection control problems. This funding will enable the CDC to engage with industry and academia through extramural grant mechanisms to:

- Examine current technologies and practices that eliminate the risk of human error through unsafe injection practices;
- Identify and develop fast tracked safety engineered-solutions for next generation products; and
- Demonstrate effectiveness of new technology to support inclusion in Federal guidelines.

Detection, Tracking, and Response (\$14 million)

Funds to expand augmentation of CMS survey capacity in outpatient settings to strengthen state capacity to detect infections that indicate errors in injection practices. These funds will enable the CDC, in collaboration with CMS, to expand surveillance in states by providing training tools for surveyors, health department staff and epidemiologists to improve methods of monitoring adherence to correct practices and to provide tools for investigation, response and intervention strategies. Funds to assist state and local health departments implement State HAI Action Plans, including detection and tracking

in order to investigate outbreaks of healthcare-associated infections and other adverse events related to injection safety.

Funds to enable the CDC to provide assistance and respond to outbreaks resulting from the re-use of syringes as requested by health departments and health systems. Funds to the CDC to develop CDC Toolkits of best practices for patient notifications and post-notification support and best practices for investigations and detecting clusters of outbreaks, to be used by state and local health departments and health care systems.

2) Encouraging HHS to Focus on HAIs in the Outpatient Setting

HONORreform requests \$1 million for the Department of Health and Human Services (HHS) to expand its current focus for reducing healthcare acquired infections (HAIs) from hospitals to outpatient settings with the development of an action plan to reduce HAIs in outpatient settings with a specific focus on injection safety. HONORreform is concerned with the number of HAIs occurring in office-based settings, such as ambulatory care centers, infusion centers, and endoscopy clinics, due to a lack of adherence to basic infection control procedures. In two years, more than 150,000 patients in the United States have received ominous letters from public health officials warning of possible exposure to deadly diseases like hepatitis and HIV because their providers failed to follow fundamental safety measures. The increased frequency of such outbreaks was highlighted in the February 2010 article, "US Outbreak Investigations Highlight the Need for Safe Injection Practices and Basic Infection Control", published in *Clinics in Liver Disease*. The article attributed these outbreaks to lapses in basic infection control (i.e., syringe reuse and misuse of single dose and multidose vials).

HAIs in the Outpatient Setting (\$1 million)

Funds to expand HHS' current focus for reducing healthcare-associated infections (HAIs) from hospitals to outpatient settings with the development and implementation of an action plan to reduce HAIs in unlicensed outpatient settings and Health Resources and Services Administration (HRSA) Community Care Centers including a specific focus on injection safety. Funds to increase education, certifications and continuing education of medical, nursing, and allied health professionals, including state based certification, related to injection safety.



April 16, 2010

The Honorable David Obey
 US House of Representatives Committee on Appropriations
 Subcommittee on Labor, Health and Human Services, Education, and Related
 Agencies
 Washington, DC 20515

The Honorable Tom Harkin
 US Senate Committee on Appropriations
 Subcommittee on Labor, Health and Human Services, Education and Related
 Agencies
 Washington, DC 20510

Dear Congressman Obey and Senator Harkin:

On behalf of the HIV Health and Human Services Planning Council of New York City, I write to urge you to increase funding for Ryan White Programs by \$810.5 million over the Fiscal Year 2010 appropriated levels in the FY 2011 Labor-HHS-Education, Transportation-HUD, and Financial Services appropriations bills.

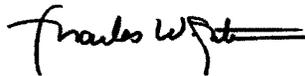
The HIV Health and Human Services Planning Council of New York is comprised of people living with HIV/AIDS, advocates, physicians, and service providers and prioritizes the allocation of Ryan White funds for treatment and care services for PLWHAs. Council Members are well versed in the challenges confronting people living with this illness and know that Ryan White HIV/AIDS Programs provide life-extending medical care, mental health and drug treatment, and support services to approximately 577,000 low-income, uninsured and underinsured individuals and families affected by HIV/AIDS each year. Your proposed FY 2011 budget requests \$2.33 billion for the Ryan White Program, but Planning Council members believe that more funding is needed in order to maintain a comprehensive system of care. Specifically, Planning Council members recommend the following increases:

- Part A: an increase of \$225.9 million for grants to eligible metropolitan areas and transitional grant areas

- Part B: an increase of \$55.9 million for care grants to state, territories, and emerging communities
- Part B AIDS Drug Assistance Program: an increase of \$370.1 million to provide life-saving medications to over 166,000 individuals already enrolled in the program and the hundreds that are currently on waiting lists in 11 states
- Part C: an increase of \$131 million for early intervention services and capacity development grants
- Part D: an increase of \$7 million for women, infants, youth, and their families
- Part F/Dental: an increase of \$5.4 million for Dental School Reimbursement Programs and the Community-Based Dental Partnership Program and
- Part F/AETC: an increase of \$15.2 million for AIDS Education and Training Centers

My fellow Planning Council members join me in thanking you for your support and commitment to improving the lives of people living with HIV/AIDS and strongly encourage you to increase the amount of money to support treatment and care services.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Charles W. Shorter", with a double horizontal line underneath the name.

Charles W. Shorter, MSW
Community Co-Chair
HIV Health and Human Services Planning Council of New York

***Testimony Submitted for the Record to the Subcommittee on
Labor, Health and Human Services, Education and Related Agencies
on FY 2011 Appropriations for HIV/AIDS Programs
Submitted by the HIV Medicine Association
Andrea Weddle, Executive Director
aweddle@hivma.org
April 7, 2010***

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 3,700 physicians, scientists and other health care professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS throughout the U.S., lead HIV prevention programs and conduct research to develop effective HIV prevention and treatment options. We work in communities across the country and around the globe as medical providers and researchers dedicated to the field of HIV medicine. We appreciate the fiscal challenges that Congress currently faces, but the state of the economy makes it imperative that our nation have a strong health care safety-net, effective programs for preventing infectious diseases like HIV and a vibrant scientific research agenda.

The U.S. investment in HIV/AIDS programs has revolutionized HIV care globally making HIV treatment one of the most effective medical interventions available. A robust research agenda and rapid public health implementation of scientific findings have transformed the HIV epidemic, reducing morbidity and mortality due to HIV disease by nearly 80 percent in the U.S. The Ryan White program has played a critical role in ensuring that many low income people with HIV have access to lifesaving HIV treatment. However, the impact of our diminished investment in public health and research programs over the last several years has taken its toll in communities across the country. HIV clinics are cutting hours and services while the number of their new HIV patients continues to increase dramatically in some areas.

Implementation of health care reform and the Administration's plans for a National HIV/AIDS Strategy offer promise for making significant progress in reducing the impact of the domestic HIV epidemic. However, their success will depend on adequate investments in shoring up the frayed health care safety net, prevention and public health and research programs. The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to sustain and strengthen our investment in combatting HIV disease.

Center for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

HIVMA strongly supports an increase of **\$1.13 billion in funding for the CDC's NCHHSTP** with an increase of **\$878 million for HIV prevention and surveillance, an increase of \$30.7 million for viral hepatitis and \$76.3 million for Tuberculosis prevention.**

Every nine and a half minutes a new HIV infection happens in the U.S. with more than 60 percent of new cases occurring among African Americans and Hispanic/Latinos. Despite the known benefit of effective treatment, 21 percent of people living with HIV in the U.S. are still not aware of their status and as many as 36 percent of people newly diagnosed with HIV progress to AIDS within one year of diagnosis. An infusion of HIV prevention funding is critical to restore and enhance HIV prevention programs by increasing support for cooperative agreements with state and local health departments; optimizing core surveillance cooperative agreements with health departments and expanding HIV testing in key health care and non health care venues by funding testing infrastructure and the purchase of approved testing devices, including rapid HIV tests and confirmatory testing and supporting linkage to care. A failure to invest now in HIV prevention will be costly. The CDC estimates that the 56,300 new HIV infections each year in the U.S. may result in \$56 billion in medical care and lost productivity.

While we appreciate that the President proposed a \$31 million increase for HIV prevention at the CDC, a much more robust investment is needed to significantly reduce the number of new HIV occurring annually in the U.S. We strongly support the CDC initiative to integrate HIV screening into medical care as an important component of the prevention portfolio. Increased HIV screening with linkage to care and treatments will help lower HIV incidence and prevalence in the U.S. Effective treatment reduces the virus to very low levels in the body, and there is a growing body of evidence suggesting that treatment can reduce risk of HIV transmission. Furthermore through education, counseling and treatment, individuals who are aware that they have HIV are more likely to adopt behaviors to prevent transmission of the virus. The transmission rates among people who know their status is 1.7 percent to 2.4 percent compared to transmission rates of 8.8 percent to 10.8 percent for those who are unaware they are infected with HIV. A significant investment of federal resources is necessary to support state health departments, medical institutions, community health centers and other community based organizations with implementing these programs and for their full potential to be realized – particularly in light of steep state budget cuts.

Identifying people with HIV earlier through routine HIV testing and linking them to HIV care saves lives and also is more cost effective for the health care system. One study found that people living with HIV disease receiving care at the later stages of the disease expended 2.6 times more in health care dollars than those receiving treatment according to the standard of care recommended in the federal HIV treatment guidelines.

Finally, we also must increase support for science-based, comprehensive sex education programs. We are pleased that Congress took important steps in the FY2010 appropriations process to discontinue funding for unproven abstinence-only sex education programs and shift those funds to support comprehensive, age-appropriate sex education programs. We also support shifting administration of those funds to the Department of Health and Human Services' Office of Adolescent Health. However, we are concerned that by focusing the funding on teenage pregnancy prevention alone, and not including the equally important health issues of STIs and HIV, both the Administration and Congress missed an opportunity to provide true,

comprehensive sex education that promotes healthy behaviors and relationships for all young people, including lesbian, gay, bisexual, and transgender youth. We urge the Committee to adopt report language that broadens the scope of the new teen pregnancy prevention program to include an explicit focus on prevention of STDs including HIV.

CDC-Tuberculosis

Tuberculosis is the major cause of AIDS-related mortality worldwide. Two years ago, Congress passed landmark legislation in the Comprehensive Tuberculosis Elimination Act of 2008. This bill authorizes a number of actions that will shore up state TB control programs, enhance U.S. capacity to deal with the serious threat of drug-resistant tuberculosis, and escalate our efforts to develop urgently needed “tools,” such as drugs, diagnostics and vaccines. Realizing these goals will require additional resources. Unfortunately, the Administration has proposed a cut of \$1.2 million for domestic TB control. At a minimum, it is critical that the authorized funding level of \$220.5million be appropriated for the CDC Division of TB Elimination. The bill also separately authorized \$100 million for development of TB diagnostics, treatments and prevention tools, which HIVMA also supports for inclusion in FY2011 appropriations.

Two years ago, Congress passed landmark legislation—the Comprehensive Tuberculosis Elimination Act of 2008—Public Law 110-873 that authorizes a number of actions that will shore up state TB control programs, enhance US capacity to deal with the serious threat of drug-resistant tuberculosis and escalate our efforts to develop urgently needed new “tools” in the form of drugs, diagnostics and vaccines. It is critical that the **\$220.5 million in funding authorized for FY 2011** in this important law is appropriated for the CDC Division of TB Elimination. This represents an increase of \$76.3 million over current funding levels. Funding to support the prevention, control and elimination of tuberculosis must increase substantially if we are going to make headway against this deadly disease and to address the emerging threat of highly drug resistant tuberculosis.

CDC-Viral Hepatitis

Funds are urgently needed to provide core public health services and to track chronic cases of hepatitis. Hepatitis is a serious co-infection for nearly one-third of our HIV patients. We strongly urge you to **boost funding for viral hepatitis at the CDC by \$31 million for a total funding of \$50 million.**

HIV/AIDS Bureau of the Health Resources and Services Administration

We strongly urge you to increase funding for the Ryan White program by \$811 million in fiscal year 2011 with at least an increase of \$131 million for Part C for a total Ryan White appropriation of \$3.1 billion. Ryan White Part C funds comprehensive HIV care and treatment— the medical services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. While the patient caseload in Part C

programs has been rising, funding for Part C has effectively decreased due to flat funding and funding cuts at the clinic level. Part C programs expect a continued increase in patients due to higher diagnosis rates and economic -related declines in insurance coverage. During this economic downturn people with HIV across the country are relying on Part C comprehensive services more than ever. The HIV medical clinics funded through Part C have been in dire need of increased funding for years, but new pressures are creating a crisis in communities across the country. An increase in funding is critical to prevent additional staffing and service cuts and ensure the public health of our communities.

Minimal annual increases in Ryan White Part C allocations have lagged behind rapid cost increases in all aspects of health care delivery programs, leaving Part C programs operating at a deficit while struggling to meet growing patient need. Part C programs provide comprehensive primary care to more than 240,000 HIV patients – which represents an increase of more than 30% in less than 10 years. Part C clinics are laying off staff, curtailing critical services such as laboratory monitoring, creating waitlists, and operating on a 4-day work week just to get by. For FY 2011, HIVMA joins the Ryan White Medical Provider Coalition, The CAEAR Coalition, and the American Academy of HIV Medicine to request a \$131 million funding increase for Part C programs. These funds are urgently needed to provide HIV care and treatment to Part C patients nationwide. HIVMA strongly supports the effort led by the Ryan White Medical Providers Coalition to **double funding for Ryan White Part C programs by Fiscal Year 2012**. These funds are critical to meet the needs of HIV patients served by Part C programs around the country.

Agency for Health Care Quality and Research (AHRQ)

HIVMA strongly urges full funding of \$1.95 million for the HIV Research Network (HIVRN), which represents the only significant HIV work being done at AHRQ. The HIVRN is a consortium of 18 HIV primary care sites co-funded by AHRQ and HRSA to evaluate health care utilization and clinical outcomes in HIV infected children, adolescents and adults in the US. The Network analyzes and disseminates information on the delivery and outcomes of health care services to people with HIV infection. These data help to improve delivery and outcomes of HIV care in the U.S. and to identify and address disparities in HIV care that exist by race, gender, and HIV risk factor. The HIVRN is a unique source of information on the cost and cost-effectiveness of HIV care in the U.S. at a time when data on comparative cost and effectiveness of health care is particularly needed to inform health systems reform and the development and implementation of a National HIV/AIDS Strategy. The HHS budget retained the HRSA share of HIVRN funding (\$.4 million) but inexplicably zeroed out the AHRQ funding for the program, without any policy rationale for eliminating it.

National Institutes of Health (NIH) – Office of AIDS Research

HIVMA strongly supports an increase of at least \$4 billion for all research programs at the NIH, including at least a \$500 million increase for the NIH Office of AIDS. This level of funding

is vital to sustain the pace of research that will improve the health and quality of life for millions of Americans. HIVMA strongly supported the infusion of NIH research dollars included in the economic recovery bill. The desperately needed funding came at a critical time to sustain our nation's scientific research capacity while stimulating the economy in communities across the country. Prior to the boost in NIH funding, the declining US investment in biomedical research had taken its toll in deep cuts to clinical trials networks and significant reductions in the numbers of high quality, investigator-initiated grants that were approved. With only one in four research applications receiving funding, the pipeline for critical discoveries and HIV scientists has been dwindling and our role as a leader in biomedical research is at serious risk.

Our past investment in a comprehensive portfolio was responsible for the dramatic gains that we made in our HIV knowledge base, gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. Gains that also helped us to reduce the mother to child HIV transmission rate from 25 percent to nearly 1 percent in the U.S. and to very low levels in other countries where treatment is available.

A continued robust AIDS research portfolio is essential to sustain and to accelerate our progress in offering more effective prevention technologies; developing new and less toxic treatments; and supporting the basic research necessary to continue our work developing a vaccine that may end the deadliest pandemic in human history. The sheer magnitude of the number of people affected by HIV—more than one million people in the U.S.; more than 33 million people globally—demands a continued investment in AIDS research if we are going to truly eradicate this devastating disease. We believe a high priority should be research to discover novel prevention strategies, to improve available treatment strategies, to aid prevention and to maximize the benefits of antiretroviral therapy, especially in the populations disproportionately affected by HIV in the U.S. and in resource-limited settings.

Historically, our nation has made significant strides in responding to the HIV pandemic here at home and around the world, but we have lost ground in recent years, particularly domestically, as funding priorities have shifted away from public health and research programs. We appreciate the many difficult decisions that Congress faces this year, but urge you to recognize the importance of investing in HIV prevention, treatment and research now to avoid the much higher cost that individuals, communities and broader society will incur if we fail to support these programs. We must seize the opportunity to limit the toll of this deadly infectious disease on our planet and to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe.

House Committee on Appropriations
 Subcommittee on Labor HHS
 The Humane Society of the United States
 on the FY 2011 Budget
 April 16, 2010

**HOUSE COMMITTEE ON APPROPRIATIONS
 SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
 EDUCATION AND RELATED AGENCIES**

**TESTIMONY BY NANCY PERRY, VICE PRESIDENT OF GOVERNMENT AFFAIRS FOR
 THE HUMANE SOCIETY OF THE UNITED STATES
 ON THE FY 2011 BUDGET – NATIONAL INSTITUTES OF HEALTH
 April 16, 2010**

*Contact: Lauren Silverman, Federal Legislative Specialist, The Humane Society of the U.S.
 519 C Street NE, Washington, DC 20002~ 202.955.3675/lsilverman@humanesociety.org*

On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), and our joint membership of over 11 million supporters nationwide, we appreciate the opportunity to provide testimony on our top funding priority for the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in Fiscal Year 2011.

BREEDING OF CHIMPANZEES FOR RESEARCH

The HSUS requests that no federal funding be appropriated for the breeding of chimpanzees for research. The basis of our request can be found below.

- The National Center for Research Resources (NCRR) of the National Institutes of Health (NIH), responsible for the oversight and maintenance of federally-owned chimpanzees, placed a moratorium on funding the breeding of federally owned and supported chimpanzees in 1995, primarily due to the excessive costs of lifetime care of chimpanzees in laboratory settings. NCRR made this moratorium permanent in 2007. As a result, no federally owned chimpanzees should have given birth or sired infants since 1995 and no federally owned chimpanzees should have a date of birth later than 1995. We have discovered, however, that the government has provided millions of dollars in recent years for chimpanzee breeding. Therefore, we seek to ensure that neither the NIH nor any other federal agency provides funding for breeding of government-owned chimpanzees due to the future financial implications to the government and taxpayers of continuing to do so, particularly during this difficult economic time.
- According to records obtained from the New Iberia Research Center (NIRC), 42 federally owned females and 9 federally-owned males have been used for breeding since the 1995 moratorium was put into place. Furthermore, at least 29 infants were born to a federally owned mother and/or federally owned father since 1995 and 27 federally-owned chimpanzees have a date of birth after 1995.
- There is evidence that chimpanzees being bred by the New Iberia Research Center (NIRC) – through their contract with the National Institute of Allergy and Infectious Diseases

House Committee on Appropriations
Subcommittee on Labor HHS
The Humane Society of the United States
on the FY 2011 Budget
April 16, 2010

(NIAID) –are owned or supported by NCRR, and as a result, in violation of NCRR's breeding moratorium.

- The cost of maintaining chimpanzees in laboratories is exorbitant, totaling up to \$28 million each year for the current population of approximately 800 federally owned or supported chimpanzees (up to \$67 per day per chimpanzee; over \$1,000,000 per chimpanzee's 60-year lifetime). Breeding of additional chimpanzees into laboratories will only perpetuate a number of burdens on the government.
- The U.S. currently has a surplus of chimpanzees available for use in research due to overzealous breeding for HIV research and subsequent findings that they are a poor HIV model.¹
- Expansion of the chimpanzee population in laboratories only creates more concerns than presently exist about their quality of care.
- Use of chimpanzees in research raises strong public concerns.

Background and History

Beginning in 1995, the National Research Council (NRC) confirmed a chimpanzee surplus and recommended a moratorium on breeding of federally owned or supported chimpanzees¹, who now number approximately 800 of the more than 1000 total chimpanzees available for research in the U.S. On May 22, 2007 the NCRR of NIH announced a permanent end to the funding of chimpanzee breeding, which applies to all federally-owned and supported chimpanzees.. Further, it has also been noted that "a huge number" of chimpanzees are not being used in active research protocols and are therefore "just sitting there."² If no breeding is allowed, it is projected that the government will have almost no financial responsibility for the chimpanzees it owns within 30 years due to the age of the population—any breeding today will extend this financial burden to 60 years.

There is no justification for breeding of additional chimpanzees for research; therefore lack of federal funding for breeding will ensure that no breeding of federally owned or supported chimpanzees for research will occur in FY 2011.

Concerns regarding chimpanzee care in laboratories

A nine month undercover investigation by The HSUS at University of Louisiana at Lafayette New Iberia Research Center (NIRC)—the largest chimpanzee laboratory in the world—revealed some chimpanzees living in barren, isolated, conditions and documented over 100 alleged violations of the Animal Welfare Act at the facility in regards to chimpanzees. The U.S. Department of Agriculture (USDA) and NIH's Office of Laboratory Animal Welfare (OLAW) have since launched formal investigations into the facility and NIRC was cited for several violations of the Animal Welfare Act during an initial site visit.

Aside from the HSUS investigation, inspections conducted by the USDA demonstrate that basic chimpanzee standards are often not being met. Inspection reports for other federally funded chimpanzee facilities have reported violations of the Animal Welfare Act in recent years, including the death of a chimpanzee during improper transport, housing of chimpanzees in less than minimal space requirements, inadequate environmental enhancement, and/or general disrepair of facilities. These problems add further argument against the breeding of even more chimpanzees.

Chimpanzees have often been a poor model for human health research

The scientific community recognizes that chimpanzees are poor models for HIV because chimpanzees do not develop AIDS. Similarly, chimpanzees do not model the course of the human hepatitis C virus yet they continue to be used for this research, adding to the millions of dollars already spent without a sign of a promising vaccine. According to the chimpanzee genome, some of the greatest differences between chimpanzees and humans relate to the immune system³, calling into question the validity of infectious disease research using chimpanzees.

Ethical and public concerns about chimpanzee research

Chimpanzee research raises serious ethical issues, particularly because of their extremely close similarities to humans in terms of intelligence and emotions. Americans are clearly concerned about these issues: 90% believe it is unacceptable to confine chimpanzees individually in government-approved cages (as we documented during our investigation at NIRC); 71% believe that chimpanzees who have been in the laboratory for over 10 years should be sent to sanctuary for retirement⁴; and 54% believe that it is unacceptable for chimpanzees to “undergo research which causes them to suffer for human benefit.”⁵

We respectfully request the following bill or committee report language:

“The Committee directs that no funds provided in this Act be used to support the breeding of chimpanzees for research.”

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2011. We hope the Committee will be able to accommodate this modest request that will save the government a substantial sum of money, benefit chimpanzees, and allay some concerns of the public at large. Thank you for your consideration.

References

1. NRC (National Research Council) (1997) *Chimpanzees in research: strategies for their ethical care, management and use*. National Academies Press: Washington, D.C.
2. Cohen, J. (2007) Biomedical Research: The Endangered Lab Chimp. *Science*. 315:450-452.
3. The Chimpanzee Sequencing and Analysis Consortium/Mikkelsen, TS, *et al.*, (1 September 2005) Initial sequence of the chimpanzee genome and comparison with the human genome, *Nature* 437, 69-87.

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4. 2006 poll conducted by the Humane Research Council for Project Release & Restitution for Chimpanzees in laboratories
5. 2001 poll conducted by Zogby International for the Chimpanzee Collaboratory

**HIGH THROUGHPUT SCREENING, TOXICITY PATHWAY PROFILING, AND BIOLOGICAL
INTERPRETATION OF FINDINGS
NATIONAL INSTITUTES OF HEALTH – OFFICE OF THE DIRECTOR**

In 2007, the National Research Council published its report titled “Toxicity Testing in the 21st Century: A Vision and a Strategy.” This report catalyzed collaborative efforts across the research community to focus on developing new, advanced molecular screening methods for use in assessing potential adverse health effects of environmental agents. It is widely recognized that the rapid emergence of omics technologies and other advanced technologies offers great promise to transform toxicology from a discipline largely based on observational outcomes from animal tests as the basis for safety determinations to a discipline that uses knowledge of biological pathways and molecular modes of action to predict hazards and potential risks.

In 2008, NIH, NIEHS and EPA signed a memorandum of understanding^[1] to collaborate with each other to identify and/or develop high throughput screening assays that investigate “toxicity pathways” that contribute to a variety of adverse health outcomes (e.g., from acute oral toxicity to long-term effects like cancer). In addition, the MOU recognized the necessity for these federal research organizations to work with “acknowledged experts in different disciplines in the international scientific community.” Much progress has been made, but there is still a significant amount of research, development and translational science needed to bring this vision forward to where it can be used with confidence for safety determinations by regulatory programs in the government and product stewardship programs in the private sector. In particular, there is a growing need to support research to develop the key science-based interpretation tools which will accelerate using 21st century approaches for predictive risk analysis. We believe the Office of the Director at NIH can play a leadership role for the entire US government by funding both extramural and intramural research.

We respectfully request the following committee report language:

"The Committee supports the implementation of the National Research Council's report "Toxicity Testing in the 21st Century: A Vision and a Strategy" to create a new paradigm for risk assessment based on use of advanced molecular biological methods in lieu of animal toxicity tests and urges the National Institutes of Health to play a leading role by funding relevant intramural and extramural research projects. Current activities at the NIH Chemical Genomics Center, National Institute of Environmental Health Sciences and the Environmental Protection Agency show considerable potential and the NIH Director should explore opportunities to augment this effort by identifying possible additional resources that could be directed to key extramural research projects."

^[1] <http://www.genome.gov/pages/newsroom/currentnewsreleases/ntpncgcepamou121307finalv2.pdf>



Industrial Minerals Association — North America

Written Testimony

Submitted by

Mark G. Ellis
President
Industrial Minerals Association – North America
202.457.0200
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To the

Subcommittee on Labor, Health and Human Services, Education,
and Related Agencies
Committee on Appropriations
U.S. House of Representatives

Regarding the

Mine Safety and Health Administration
U.S. Department of Labor

April 13, 2010

The Honorable David R. Obey
Chairman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
U.S. House of Representatives
2314 Rayburn House Office Building
Washington, DC 20515

The Honorable Todd Tiahrt
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
U.S. House of Representatives
2441 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Obey and Ranking Member Tiahrt:

I write to request additional appropriations for the Department of Labor's Mine Safety and Health Administration (MSHA). Specifically the Industrial Minerals Association – North America (IMA-NA) requests a one-time appropriation of \$3.6 million to improve MSHA's

communication capabilities, specifically videoconferencing capabilities, and \$1.7 million annually thereafter to maintain and operate these enhanced communications capabilities. This funding level is adequate to establish enhanced communications capabilities at 20 sites nationally and capable of reaching directly fully 80 percent of MSHA's approximately 2,500 employees.

It generally is recognized that mine inspectors need to stay abreast of the latest developments in mine safety, be informed of changes in regulatory standards and interpretations, be able to learn from mine incidents from various parts of the country, and feel a sense of connectedness with their headquarters in Arlington, VA. In light of recent tragic events in West Virginia, these constituent components of MSHA's mission take on added poignancy. To accomplish these important tasks, MSHA needs a state-of-the-art communications system. MSHA should be able to instantly and effectively communicate with, train and retrain its inspectors over distance.

You may be aware that the Department of Labor's Office of Inspector General recently released an audit report regarding "Journeyman Mine Inspectors Do Not Receive Mandated Periodic Retraining." Report Number 05-10-001-06-001 (<http://www.oig.dol.gov/public/reports/oa/2010/05-10-001-06-001.pdf>). The additional appropriations requested for enhanced communications capabilities could go a long way toward addressing issues raised in this report.

The communications systems relied upon by MSHA are antiquated and ineffective. MSHA is relying on dated communications and IT infrastructure that is decades behind the capabilities of those they regulate. They also are substandard when compared to those of the National Institute for Occupational Safety and Health, the mine safety and health research agency that supports MSHA's mission. This is not acceptable.

Similarly, MSHA's ability to perform meaningful stakeholder education and outreach demands state-of-the-art communications systems. Adequately trained inspectors and consistency of enforcement are necessary components of MSHA's mission and the lack of appropriate information technology infrastructure frustrates their full implementation. Less than full implementation frustrates stakeholders. For instance, the enhanced communications capability requested could allow a mine operator at a locally convenient site to consult with MSHA officials at a distant site. Similarly, the enhanced communications capabilities could be used broadly, permitting MSHA to educate stakeholders and perform industry outreach by district, regionally and nationally, benefitting mine operators and miners alike.

IMA-NA respectfully requests your support for additional funding to improve MSHA's communication capabilities, specifically videoconferencing capabilities.

The Industrial Minerals Association – North America (IMA-NA) is a trade association organized to advance the interests of North American companies that mine or process industrial minerals. These minerals are used as feedstocks for the manufacturing and agricultural industries and are used to produce essential products. Industrial minerals are critical to the manufacture of glass, ceramics, paper, plastics, rubber, insulation, pharmaceuticals and cosmetics. They also are used to make foundry cores and molds used for metal castings, and in paints, filtration, metallurgical applications, refractory products and specialty fillers. The IMA-NA membership includes producers of ball clay, barite, bentonite, borates, calcium carbonate, diatomite, feldspar, industrial sand, magnesia, mica, soda ash (trona), talc, wollastonite and other minerals. IMA-

787

NA's membership also includes many of the suppliers to the industrial minerals industry, including equipment manufacturers, railroads and trucking companies, and consultants. Finally, the following hyperlink will direct you to our Website, which provides additional information on this important mining sector (<http://www.ima-na.org>).

Thank you for your timely consideration of this request.

Sincerely,

A handwritten signature in black ink, appearing to read "Mark G. Ellis".

Mark G. Ellis
President

cc: Members, Subcommittee on Labor,
Health and Human Services, Education,
and Related Agencies, Committee on
Appropriations, U.S. House of Representatives

IDSA Contact: Michael Ochs, Government Relations Associate
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**Infectious Diseases Society of America's (IDSA)
Statement Concerning Fiscal Year 2011 Funding at the Department of Health and Human
Services, the Centers for Disease Control and Prevention, National Institutes of Health, and
Health Resources and Services Administration**

**Submitted to the House Appropriations Subcommittee on Labor, Health and Human
Services, Education and Related Agencies**

April 16, 2010

The Infectious Diseases Society of America (IDSA) appreciates this opportunity to speak in support of federal efforts to prevent, detect and respond to infectious diseases in the United States and abroad as part of the Fiscal Year (FY) 2011 funding cycle. IDSA represents more than 9,000 infectious diseases physicians and scientists devoted to patient care, prevention, public health, education, and research. Our members care for patients of all ages with serious infections, including meningitis, pneumonia, tuberculosis (TB), antibiotic-resistant bacterial infections such as methicillin-resistant *Staphylococcus aureus* (MRSA) and gram-negative bacterial infections, and emerging infections like the 2009 H1N1 virus (swine influenza).

2009 H1N1 novel Influenza virus

IDSA's leadership strongly commends Congress and the Administration for their actions in responding to the 2009 H1N1 outbreak. As the outbreak unfolded, we witnessed firsthand the importance of recent investments in a robust public health infrastructure as well as in research and product development. Specifically, we thank the Committee for the \$7.65 billion in supplemental funding it appropriated last June to support the development of a 2009 H1N1 virus vaccine and to replenish and rebuild the Strategic National Stockpile. This funding also supported state and local health departments so they could adequately respond to the 2009 H1N1 virus and other infectious diseases outbreaks. The Administration has proposed to fund some ongoing pandemic influenza activities from these supplemental monies rather than having them come through the normal FY2011 appropriations process. IDSA disagrees with this approach and urges Congress to fund these activities through the FY2011 bill.

**The 10 x '20 Initiative: Supporting New Antibiotic Research and Development and
Combating Costly Drug-Resistant Bacterial Infections**

Since antibacterial drugs (antibiotics) were first discovered and used in the 1940s to save American soldiers during World War II, they have saved millions of lives and eased patients' suffering. In fact, antibiotics are often referred to as "miracle drugs," since patients only need to take them for a few days to completely resolve most infections. However, antibiotics also are unique among all medicines in two very unfortunate ways. First, over time, these drugs lose their ability to treat the diseases for which they were approved—due to antibiotic resistance, a serious patient safety, public health, and national security issue. Second, the phenomenon of antibiotic resistance requires that newly approved antibiotics be used sparingly so that we can prolong their effectiveness against life-threatening infections.

Unfortunately, this combination of factors—antibiotic resistance, protective measures, and antibiotics ability to cure many, but not all, infections in a matter of few days—has resulted in a market failure with the result that most pharmaceutical companies have withdrawn from antibiotic research and development (R&D) to pursue more lucrative markets such as treatments for chronic diseases. The sad result—the antibiotic pipeline is drying up, placing Americans and other people around the world at serious risk. In the January 2009 issue of the journal *Clinical Infectious Diseases (CID)*, IDSA confirmed the antibiotic pipeline is bare particularly for drugs needed to address antibiotic-resistant bacteria known as the ESKAPE pathogens (*Enterococcus faecium*, *Staphylococcus aureus*, *Klebsiella pneumoniae*, *Acinetobacter baumannii*, *Pseudomonas aeruginosa*, and *Enterobacter* species), so-called because they effectively escape the effects of approved antibiotic drugs. In September 2009, the European Centre for Disease Prevention and Control (ECDC) and the European Medicines Agency (EMA) released their own report affirming IDSA's assessment and found only 15 antibiotic drugs in development that may provide benefit over existing antibiotics. Based on past experiences, we know most of these drugs will never make it across the finish line to approval.

For nearly a decade, IDSA has raised concerns about the imbalance between the dwindling antibiotic pipeline and the significant need for new antibiotics to treat an increasing number of drug-resistant infections. The current situation has created very real challenges in physicians' ability to treat infectious diseases caused by ESKAPE pathogens, which have resulted in pain, suffering, and disfigurement in adults, children and infants, and hundreds of thousands of deaths.

In response to the antibiotic pipeline crisis, IDSA has launched the 10 x '20 initiative; the inaugural statement appears in the April 15th issue of CID. The goals of this initiative are simple to articulate, but will be difficult to achieve. We need a global commitment by the U.S. government, particularly the Department of Health and Human Services (HHS), and other governments to create a sustainable antibiotic R&D enterprise, which in the short-term can produce 10 new safe and effective antibiotics by 2020. To achieve the 10 x '20 goal, it will be necessary to bring together experts from the industrial, medical, scientific, policy, regulatory, and financial communities to determine the right combination of incentives that will work. We urge the Subcommittee to adopt the 10 x '20 goal as its own and make new antibiotic research and development a key element of its funding for HHS for Fiscal Year 2011.

Antibiotic-resistant infections significantly increase both health care and societal costs. A recent analysis of antibiotic-resistant infection data conducted at Chicago Cook County Hospital (*CID*, October 2009) showed that the direct and indirect economic costs of antibiotic resistance are enormously high in terms of dollars and length of hospital stays. Extrapolating the analysis nation-wide¹, the authors concluded that antibiotic-resistant infections cost the U.S. health care system in excess of \$20 billion annually as well as more than \$35 billion in societal costs and more than eight million additional days spent in the hospital. Another study published in *Antimicrobial Agents and Chemotherapy* (January 2010), found that total hospital costs and length of stays attributable to antibiotic-resistant healthcare-associated infections (HAIs) caused by gram-negative pathogens (a segment of the ESKAPE pathogens) were 29.3 percent and 23.8 percent higher than those attributable to HAIs caused by antibiotic-susceptible gram-negative

¹ <http://www.prnewswire.com/news-releases/antibiotic-resistant-infections-cost-the-us-healthcare-system-in-excess-of-20-billion-annually-64727562.html>.

pathogens, respectively. Another study in *Infection Control and Hospital Epidemiology* (April 2010) found that the cost of treating patients with MRSA, an ESKAPE pathogen, was significantly higher than treating patients with methicillin-susceptible *S. aureus* (MSSA). The median cost for six months of treatment of an MRSA infection was \$34,657 compared to \$15,923 for treatment of an MSSA infection. The higher costs were the result of longer hospital stays, more laboratory and imaging tests, and more rehabilitation services.

To address infections caused by antibiotic-resistant ESKAPE pathogens and other infectious diseases, including on-going threats from H1N1 and other types of influenza, we need the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), National Institutes of Health (NIH), and Biomedical Advanced Research and Development Authority (BARDA) to be robust and fully funded.

Centers for Disease Control and Prevention

A strong CDC is essential to the United States' efforts to rapidly detect and control antibiotic resistance and infectious diseases as it is the primary federal agency responsible for conducting and supporting public health protection through health promotion, prevention, preparedness, and research. For FY2011, IDSA recommends:

- increasing funding for CDC's core programs to \$8.8 billion;
- \$40 million for CDC's Antimicrobial Resistance programs;
- \$2.3 billion for CDC's Infectious Diseases programs;
- funding of the Emerging Infectious Diseases line item be increased to \$200 million;
- \$27.45 million for the National Health Safety Network (NHSN), as requested by the Administration;
- a funding level for the Section 317 Program of \$865.5 million, with the establishment of distinct funding floors for adult vaccine purchase and infrastructure;
- \$220.5 million for the CDC Division of TB Elimination; and
- \$1.6 billion for CDC's HIV prevention programs, as well as \$3.1 billion for HRSA's Ryan White CARE Act programs and an increase in Part C medical care by \$131 million.

Within the Preparedness, Detection, and Control of Infectious Diseases program's proposed budget, CDC's already severely strapped Antimicrobial Resistance budget would be cut dramatically by \$8.6 million—just over 50 percent! This vital program is necessary to help combat the rising crisis of antibiotic resistance, which CDC has deemed "one of the world's most pressing public health problems." Yet the President's FY2011 budget would allow only 20 state/local health departments and health care systems to be funded for surveillance, prevention, and control of antimicrobial resistance, down from 48 this past year. It would also eliminate all grants to states for the successful Get Smart in the Community program to combat improper uses of antibiotics. IDSA believes CDC's antimicrobial resistance activities are so important to protecting Americans from serious and life-threatening infections that we urge you to boost funding for these activities to at least \$40 million in FY2011.

National Institutes of Health

NIH is the single-largest funding source for infectious diseases research in the United States and the life-source for many academic research centers. The NIH-funded work conducted at these

centers lays the groundwork for advancements in treatments, cures, and other medical technologies. Between 2003 and 2009, NIH lost 13 percent of its purchasing power due to the rate of biomedical research inflation and stagnating annual budgets. Because of the flat budget, three out of four research proposals submitted to NIH were not funded. IDSA is pleased that the American Recovery and Reinvestment Act provided additional funding to support NIH's research efforts in 2009 and 2010. Congress rightfully acknowledged the role of scientific research in stimulating the economy. However, it is vital that the momentum for medical research is sustained as it is essential to our national priorities of better health and economic revitalization. Therefore, IDSA supports a funding level of \$35 billion for NIH in FY2011.

Of great importance, given the scope of the antibiotic resistance/ESKAPE pathogen problem and its impact on everyday Americans, IDSA proposes a substantial funding increase in antibacterial resistance and antibacterial discovery research within NIH's National Institute of Allergy and Infectious Diseases (NIAID) to a total of \$500 million in FY2011. An IDSA analysis of 2009 NIAID funding found that, because of other serious medical problems, NIAID's total funding commitment for antibacterial resistance research was less than \$100 million. NIAID's support for antibacterial drug discovery research was less than \$70 million. Because of the rapid escalation in the problem of resistance, new initiatives must be developed. Significantly increasing funding in both areas will enable NIAID to support a better understanding of mechanisms of resistance as well as expanding joint ventures between academia and industry that will identify new drug targets and drugs with activity for those targets. In the end, we hope this will lead to the development of a library of target drug compounds that will support industry's efforts to find new antibiotics that treat infections caused by ESKAPE pathogens. Increased funding also will allow NIAID, in conjunction with other federal agencies such as BARDA, to create a seamless approach to new antibiotic drug R&D.

IDSA also is extremely pleased that the recently enacted Patient Protection and Affordable Care Act created the Cures Acceleration Network (CAN) at NIH to help move discoveries from the lab into the next generation of therapies. IDSA supports funding of at least \$500 million in FY2011 for this critically needed new initiative.

NIH's Fogarty International Center is at the forefront of global health and is a leader in extending the U.S. federal biomedical enterprise abroad. Through Fogarty, the United States has supported research and research training programs conducted by both U.S. and foreign investigators across a wide range of infectious diseases and needs, including HIV/AIDS, malaria, and tuberculosis. The Center's efforts have led to improved local health outcomes -- but so much more can be done. For this reason, IDSA strongly supports increasing Fogarty's funding level in FY2011 to \$100 million -- an increase of \$26.95 million.

Biomedical Advanced Research and Development Authority

Congress must fully fund BARDA within HHS so that the United States can begin to realize goals envisioned under the Pandemic and All-Hazards Act enacted in 2006 to address emerging infectious threats in addition to bioterrorism and pandemic influenza. IDSA recommends that at least \$1.7 billion of multi-year appropriations be allocated to BARDA in FY 2011 to fund therapeutics, diagnostics, vaccines, and other technologies, including new antibiotics to treat infections caused by the ESKAPE pathogens. Such funding would help ensure the availability of

resources throughout the advanced stages of development and the flexibility for BARDA to partner effectively with industry.

Today's investment in infectious diseases research, prevention, and treatments will pay significant dividends in the future by dramatically reducing health care costs and improving the quality of life of millions of Americans and others.

**Statement of Dr. Peter Alfonso
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**Submitted to the House Appropriations Committee
Subcommittee on Labor, Health and Human Services, and Education
May 19, 2010**

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit this statement regarding FY 2011 funding for the National Institutes of Health's Institutional Development Award or "IDeA" Program. The IDeA program is funded by NIH's National Center for Research Resources (NCRR), and was authorized by the 1993 NIH Revitalization Act (P.L. 103-43).

My name is Dr. Peter Alfonso and I am the Vice President for Research and Economic Development at the University of Rhode Island. I submit this testimony on behalf of the Coalition of EPSCoR/IDeA States¹. EPSCoR is the "Experimental Program to Stimulate Competitive Research," and IDeA, as previously stated, is the NIH's Institutional Development Award program.

IDeA is an important program because it increases our nation's biomedical research capability by improving research in states that have historically been less successful in obtaining biomedical research funds. Twenty-three states and Puerto Rico are eligible. IDeA funds only merit-based, peer-reviewed research that meets NIH research objectives.

As previously mentioned, IDeA was authorized by the 1993 NIH Revitalization Act (P.L. 103-43), but the program was funded at very low levels during its early years. However, between FY 2000 and FY 2003, IDeA grew rapidly, due in large part to the thoughtful actions of this Subcommittee. This funding permitted the initiation of two new program elements:

The first was COBRE or "Centers of Biomedical Research Excellence;" which are research clusters targeting specific biomedical research problems. The COBRE program is designed to increase the pool of well-trained investigators in the IDeA states by expanding research facilities, equipping laboratories with the latest research

¹ **Alabama, Alaska, Arkansas, Delaware, Hawaii, Idaho, Iowa, Kansas, Kentucky, Louisiana, Maine, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oklahoma, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, West Virginia, and Wyoming**

States in **bold** letters are eligible for the IDeA program. All of the states listed above are also eligible for the EPSCoR program.

equipment, providing mentoring for promising candidates, and developing research faculty through support of a targeted multi-disciplinary center, led by an established, senior investigator with expertise in the research focus area of the center.

More specifically, COBRE goals are to: (1) develop a thematic scientific focus in a research area and a prominent research center with the mission of NIH; (2) engage an established investigator, funded by NIH, NSF or other comparable Federal or private sector source to lead the effort; (3) develop the competitiveness of three to five research projects, each supervised by a junior investigator; (4) define a plan for mentoring, career development, graduation and addition of new junior investigators to the COBRE; and (5) establish long-term plans for developing and sustaining the center, research program, investigators, collaborations and physical infrastructure.

The second was BRIN or "Biomedical Research Infrastructure Networks;" which targeted key areas such as bioinformatics and genomics and facilitated the development of cooperative networks between research-intensive and primarily undergraduate colleges. The BRIN grants underwent competitive renewals in 2004 under the new name of IDeA Networks of Biomedical Research Excellence (INBRE).

INBRE increases the pipeline of outstanding students and enhances the quality of science faculty in the IDeA states by research-intensive networking and undergraduate institutions. The INBRE program supports research infrastructure and mentoring of young investigators, and prepares students for graduate and professional schools as well as careers in the biomedical sciences at participating institutions.

More specifically, INBRE goals are to: (1) build and strengthen the lead and partner institutions' biomedical research expertise and infrastructure; (2) build and increase the research base and capacity by providing research support to faculty, postdoctoral fellows, and graduate students at the participating institutions; (3) provide research opportunities for undergraduate students, and serve as a "pipeline" for undergraduate students to continue in health research careers within IDeA states; (4) provide outreach to students at undergraduate institutions, community colleges and tribal colleges participating in the state's network; and (5) enhance the science and technology knowledge of the state's workforce.

I would like to describe a few examples of how both COBRE and INBRE (formerly BRIN) grants have changed the biomedical research landscape of Rhode Island. The first COBRE award in Rhode Island was made to Brown University in 2000. Prior to this award the biomedical research infrastructure of the University was severely lacking and the interactions between researchers at Brown and at other institutions within the state were minimal at best.

The COBRE award allowed the PI to establish the "Center for Genomics and Proteomics" and to support five promising research teams each composed of a senior PI and four-to-five junior investigators. Funding provided to junior investigators using this mechanism directly and positively correlated with their success in publishing papers

(success rate went from 29 published papers to 59 published papers) and in obtaining independent research project grants (RPGs) (success rate went from 12 RPGs to 24 RPGs). State-of-the-art core facilities in microscopy, genomics, and transgenics were established and staffed with Ph.D. level directors. Seminar series and workshops were initiated with COBRE funding and served as the basis for developing collaborative ties with researchers throughout the state. The establishment of the "Center for Genomics and Proteomics" at Brown also included the purchase and renovation of significant new research space in an old industrial section of the city. This area of the city has now been filled with new businesses and is prospering.

The 2000 COBRE award was renewed for another five years and the focus is now on signaling and cancer, with the long term goal of establishing a cancer center. Four out of the five junior investigators funded on this phase II COBRE have now obtained independent research project grants. A type III COBRE that focuses on infrastructure support has been submitted, and if successful, will strengthen the ability of our researchers to perform cutting edge biomedical science in the newly designated "Knowledge" district of Providence. Since the first COBRE award to Brown University in 2000, five other COBREs have been awarded to three separate institutions: Rhode Island Hospital (three COBRE awards), Roger Williams Hospital (one COBRE), and Women and Infants Hospital (one COBRE). In all five cases, the awarded funds have directly led to the establishment of critical Core Facilities that provide new faculty with valuable access to state of the art instrumentation that they would not be able to acquire through standard grant award mechanisms. For all of these reasons, COBRE is a critical mechanism of support for states with limited budgets for research support.

The three-year BRIN grant, awarded to Rhode Island in 2001 and competitively renewed as INBRE for five years in 2004 and again in 2009, provided another mechanism for addressing both the lack of critical mass of biomedical researchers at the University of Rhode Island and other primarily undergraduate institutions in the states, and the lack of high-end state-of-the-art equipment for biomedical research at these institutions. Lack of critical mass and the necessary infrastructure to support biomedical research meant that existing researchers were unable to perform cutting edge research and effectively compete for research dollars from Federal agencies such as the National Institutes of Health. Meager startup funds available for hiring new faculty hampered efforts to recruit quality research-oriented faculty. There were limited opportunities for student training in faculty laboratories, and finally, there was a lack of the type of interinstitutional cooperation needed to create a network of biomedical researchers.

Through funding received as a result of the BRIN/INBRE awards, more than \$2 million in biomedical research equipment for genomics, proteomics and drug development studies has been purchased and housed in a renovated laboratory. This equipment is accessible to all researchers from the participating institutions: University of Rhode Island; Rhode Island College; Providence College; Roger Williams University; Salve Regina University; and Brown University. Through BRIN/INBRE funding, the Center for Molecular Toxicology at the University of Rhode Island was established. The Center

has allowed us to leverage the creation of new faculty positions at all participating institutions in the related thematic areas of toxicology, cell biology and environmental health, and helped provide competitive new faculty startup packages. New faculty research, coupled with regularly scheduled seminars and workshops, is generating increased student interest in research and also greater training opportunities for students in faculty laboratories. Greater student training in turn translates into workforce development in the biomedical and biotechnological fields.

The Rhode Island BRIN/INBRE awards have led to the creation of an effective state-wide collaborative network of biomedical researchers, which is essential for implementing an environment that will foster collaborative research. Finally, and most importantly, this funding has helped biomedical researchers in our state to achieve greater success in competing for federal research dollars. This is the ultimate goal of the IDeA program.

Despite these successes, our task is far from complete. Funding disparities between the states remain and may have a detrimental impact on our national self-interest. And that is why the IDeA program is so important. It is helping to ensure that all regions of the country participate in biomedical research. Citizens from all states should have the opportunity to benefit from the latest innovations in health care, which are most readily available in centers of biomedical research excellence.

I applaud the efforts your Subcommittee has made over the years to provide increased funding for IDeA, and hope that you will continue to invest in this program, which is so important to almost half of our states. The IDeA program is important to so many in our states, but especially to the junior investigators who are starting to become competitive for NIH funding. I think we send these young investigators the wrong message by cutting or even possibly eliminating funding for their research projects after encouraging them to pursue a career in biomedical research.

For this reason, the Coalition of EPSCoR/IDeA states believe the program should be funded at \$275 million in FY 2011. This level of funding would restore and continue funding for COBRE and INBRE, provide funding for information technology (IT) infrastructure upgrades through IDeANet, and also, some funding would be used for a co-funding program, which would allow researchers and institutions to merge with the overall national biomedical research community.

Together, the 23 States and Puerto Rico that comprise the IDeA community secured just 5% of the total NIH budget in 2010. With over 15% of the Nation's population living in the IDeA States, this figure clearly indicates the critical need for further research development and the importance of a strong IDeA program. In FY 1999, the year before COBRE grants were initiated, the 23 IDeA states and Puerto Rico received a total of \$596 million from NIH. In FY 2009 the 23 IDeA states and Puerto Rico received a total of \$1.5 billion from NIH. This is evidence the program is working and that the IDeA states are moving in the right direction. Yet, when I consider that in 2005, the top seven states that were recipients of NIH funding received over a \$1 billion each, California

alone received over \$3 billion, \$275 million for 23 states and Puerto Rico seems more than reasonable. Every region of the country has talent and expertise to contribute to our nation's biomedical research efforts – and every region of the country must participate if we are to increase our nation's biomedical research capacity substantially. On behalf of the Coalition of EPSCoR/IDeA States, I thank the Subcommittee for the opportunity to submit this testimony.

**STATEMENT OF
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**REGARDING FISCAL YEAR 2011 APPROPRIATIONS FOR THE
NATIONAL INSTITUTES OF HEALTH AND THE NATIONAL
INSTITUTES OF DIABETES AND DIGESTIVE AND KIDNEY
DISEASES**

**SUBMITTED TO THE
SENATE COMMITTEE ON APPROPRIATIONS;
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES**

APRIL 16, 2009

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2011:

- **PROVIDE A 12% FUNDING INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND CONCURRENT INCREASES ACROSS ITS INSTITUTES AND CENTERS.**
- **URGE THE NIH TO PRIORITIZE RESEARCH AND AWARENESS EFFORTS ON FUNCTIONAL GASTROINTESTINAL DISORDERS INCLUDING IRRITABLE BOWEL SYNDROME (IBS) AT THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) AND OTHER INSTITUTES AND CENTERS.**

- **ENCOURAGE THE IMPLEMENTATION OF RECOMMENDATIONS MADE BY THE NATIONAL COMMISSION ON DIGESTIVE DISEASES ON FUNCTIONAL GASTROINTESTINAL AND MOTILITY DISORDERS.**

Thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of functional gastrointestinal (GI) and motility disorders research.

Established in 1991, the IFFGD is a patient-driven nonprofit organization dedicated to assisting individuals affected by functional GI disorders, providing education and support for patients, healthcare providers, and the public at large. The IFFGD works to advance critical research to ensure better treatment options for patients suffering from functional GI disorders, with the hopes of eventually finding a cure. The IFFGD has worked closely with the NIH on a number of priorities, including the *NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults* through the NIDDK, the National Institute of Child Health and Human Development (NICHD), and the Office of Medical Applications of Research (OMAR). I also served on the National Commission on Digestive Diseases (NCDD), which released a long-range road map for digestive disease research, entitled *Opportunities and Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases*. As someone personally affected by functional GI disorders on a daily basis, the need for increased research, more effective and efficient treatments, and the hope for a cure are close to my heart.

The majority of functional GI disorders have no cure and treatment options are limited. Although progress has been made, the medical community still does not completely understand the mechanisms of the underlying conditions. Without a known cause or cure, patients suffering from functional GI disorders face a lifetime of chronic disease management, learning to adapt to painful, disruptive symptoms. The medical and indirect costs associated with these diseases are enormous; estimates range from \$25 - \$30 billion annually. Economic costs spill over into the workplace, and are reflected in work absenteeism and lost productivity. Furthermore, the human toll is not only on the individual but also on the family. Functional GI disorders do not discriminate, effecting all ages, races and ethnicities, and genders. These diseases account for significant lost opportunities for the individual as well as for society.

IRRITABLE BOWEL SYNDROME (IBS)

IBS, one of the most common functional GI disorder, strikes all demographic groups. It affects 30 to 45 million Americans, conservatively at least one out of every 10 people. Between 9 to 23% of the worldwide population suffers from IBS, resulting in significant human suffering and disability. IBS is a chronic disease is characterized by a group of symptoms that may vary from person to person, but typically include abdominal pain and discomfort associated with a change in bowel pattern, such as diarrhea and/or constipation. As a “functional disorder”, IBS affects the way the muscles and nerves work, but the bowel does not appear to be damaged on medical tests. Without a definitive diagnostic test, many cases of IBS go undiagnosed or misdiagnosed for years. It is not uncommon for IBS sufferers to have unnecessary surgery, medication, and medical devices before receiving a proper diagnosis. Even after IBS is identified, treatment

options are sorely lacking, and vary widely from patient to patient. What is known is that IBS requires a multidisciplinary approach to research and treatment.

IBS can be emotionally and physically debilitating. Due to persistent pain and bowel unpredictability, individuals who suffer from this disorder may distance themselves from social events, work, and even may fear leaving their home. Stigma surrounding bowel habits may act as barrier to treatment, as patients are not comfortable discussing their symptoms with doctors. Because IBS symptoms are relatively common and not life-threatening, many people dismiss their symptoms or attempt to self-medicate using over-the-counter medications. In order to overcome these barriers to treatment, ensure more timely and accurate diagnosis, and reduce costly unnecessary procedures, educational outreach to physicians and the general public remain key.

FECAL INCONTINENCE

At least 12 million Americans suffer from fecal incontinence. Incontinence is neither part of the aging process nor is it something that affects only the elderly. Incontinence crosses all age groups from children to older adults, but is more common among women and in the elderly of both sexes. Often it is a symptom associated with various neurological diseases and many cancer treatments. Yet, as a society, we rarely hear or talk about the bowel disorders associated with spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, uterine cancer, and a host of other diseases.

Damage to the anal sphincter muscles; damage to the nerves of the anal sphincter muscles or the rectum; loss of storage capacity in the rectum; diarrhea; or pelvic floor dysfunction can cause fecal incontinence. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Some don't want to leave the house out of fear they might have an accident in public. Most attempt to hide the problem for as long as possible. They withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly burdens families and is the primary reason for nursing home admissions, an already huge social and economic burden in our increasingly aged population.

In November of 2002, IFFGD sponsored a consensus conference entitled, *Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities*. Among other outcomes, the conference resulted in six key research recommendations including more comprehensive identification of quality of life issues; improved diagnostic tests for affecting management strategies and treatment outcomes; development of new drug treatment compounds; development of strategies for primary prevention of fecal incontinence associated with childbirth; and attention to the process of stigmatization as it applies to the experience of individuals with fecal incontinence.

In December of 2007, IFFGD collaborated with NIDDK, NICHD, and OMAR on the *NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults*. The goal of this conference was to assess the state of the science and outline future priorities for research on both fecal and urinary incontinence; including, the prevalence and incidence of fecal and urinary incontinence, risk factors and potential prevention, pathophysiology, economic and quality of life impact, current tools available to measure symptom severity and burden, and the effectiveness of both short and long term treatment. For FY 2010, IFFGD urges Congress to

review the Conference's Report and provide NIH with the resources necessary to effectively implement the report's recommendations.

GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Gastroesophageal reflux disease, or GERD, is a common disorder affecting both adults and children, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. Sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. One uncommon but serious complication is Barrett's esophagus, a potentially pre-cancerous condition associated with esophageal cancer. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. There are several treatment options available for individuals suffering from GERD. Nonetheless, treatment response varies from person to person, is not always effective, and long-term medication use and surgery expose individuals to risks of side-effects or complications.

Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year. GER results from an immature upper gastrointestinal motor development. The prevalence of GER is increased in premature infants. Many infants require medical therapy in order for their symptoms to be controlled. Up to 25% of older children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction. In this population, the natural history of GER is similar to that of adult patients, in whom GER tends to be persistent and may require long-term treatment.

GASTROPARESIS

Gastroparesis, or delayed gastric emptying, refers to a stomach that empties slowly. Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, including being present in 30% to 50% of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications, especially narcotic pain medications. In many patients the cause of the gastroparesis cannot be found and the disorder is termed idiopathic gastroparesis. Over the last several years, as more is being found out about gastroparesis, it has become clear this condition affects many people and the condition can cause a wide range of symptom severity.

CYCLIC VOMITING SYNDROME

Cyclic vomiting syndrome (CVS) is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea, vomiting, and other symptoms (abdominal pain, prostration, and lethargy) lasts hours to days. Previously thought to occur primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in a variety of age groups including adults. Patients with these symptoms often go for years without correct diagnosis. The condition leads to significant time lost from school and from work, as well as substantial medical morbidity. The cause of CVS is not known. Better understanding, through research, of mechanisms that underlie upper gastrointestinal function and motility involved in sensations of nausea, vomiting and abdominal pain is needed to help identify at risk individuals and develop more effective treatment strategies.

SUPPORT FOR CRITICAL RESEARCH

IFFGD urges Congress to fund the NIH at level of \$35 billion for FY 2011, an increase of 12% above FY 2010. This funding level will help preserve the initial investment in healthcare innovation established in the *American Recovery and Reinvestment Act of 2009* (ARRA). Strengthening and preserving our nation's biomedical research enterprise fosters economic growth, and supports innovations that enhance the health and well-being of the American people.

Concurrent with overall NIH funding, the IFFGD supports expansion of the research activities on functional GI and motility disorders at the NIH, particularly through NIDDK and the Office of Research on Women's Health (ORWH). Additional funding will allow necessary growth of the research portfolios on functional GI and motility disorders at NIDDK and ORWH. Such support would also expedite the implementation of recommendations from the National Commission on Digestive Diseases.

Following years of near level-funding at NIH, research opportunities have been negatively impacted across all NIH Institutes and Centers, including NIDDK. With the expiration of funding from the *American Recovery and Reinvestment Act* (ARRA), medical researchers run the risk of "falling off the cliff", stalling if not losing promising research from that two year period. For this reason, the IFFGD applauds and encouraged continued support for initiatives such as the Cures Acceleration Network (CAN), a provision included in the *Patient Protection and Affordable Coverage Act*. The IFFGD urges the Subcommittee to show strong leadership in pursuing a substantial funding increase through the FY 2011 appropriations process.

For FY 2011, IFFGD recommends a funding increase of 12% for NIH and its Institutes and Centers.

For FY 2011, IFFGD recommends increased support to the IBS and functional GI disorders research portfolio within NIDDK, accounting for their prevalence among GI disorders.

For FY 2011, IFFGD encourages NIH to accelerate the implementation of recommendations from the National Commission on Digestive Diseases, regarding functional and motility disorders.

Thank you for the opportunity to present the views of the functional GI disorders community.

Statement of Gregory E. Conrad, Executive Director, Interstate Mining Compact Commission regarding the FY 2011 Budget Request of the Mine Safety and Health Administration (MSHA) within the U.S. Department of Labor

Gregory E. Conrad, Executive Director
Interstate Mining Compact Commission
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Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies of the House Appropriations Committee

We are writing in support of the Fiscal Year 2011 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to support a full appropriation for grants to states for safety and health training of our Nation's miners pursuant to section 503(a) of the Mine Safety and Health Act of 1977. MSHA's budget request for state grants is \$8.941 million. This is the same amount that has been appropriated for state training grants by Congress over the past two fiscal years and, as such, does not fully consider inflationary and programmatic increases being experienced by the states. We therefore urge the subcommittee to restore funding to the statutorily authorized level of \$10 million for state grants so that states are able to meet the training needs of miners and to fully and effectively carry out state responsibilities under section 503(a) of the Act.

The Interstate Mining Compact Commission is a multi-state governmental organization that represents the natural resource, environmental protection and mine safety and health interests of its 24 member states. The states are represented by their Governors who serve as Commissioners.

IMCC's member states are concerned that without full funding of the state grants program, the federally required training for miners employed throughout the U.S. will suffer. States are struggling to maintain efficient and effective miner training and certification programs in spite of increased numbers of trainees and the incremental costs associated therewith. State grants have flattened out over the past several years and are not keeping pace with inflationary impacts or increased demands for training. The situation is of particular concern given the enhanced, additional training requirements growing out of the recently enacted MINER Act and MSHA's implementing regulations.

As you consider our request to increase MSHA's budget for state training grants, please keep in mind that the states play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) in meeting their required training needs.

We appreciate the opportunity to submit our views on the MSHA budget request as part of the overall Department of Labor budget. Please feel free to contact us for additional information or to answer any questions you may have.

**Statement of
Harry P. Selker, MD, MSPH
Dean, Tufts Clinical and Translational Science Institute
Executive Director, Institute for Clinical Research and Health Policy Studies
Tufts University and Tufts Medical Center, Boston, MA**

**On Behalf of
Join Advocacy Coalition of the:**

**Association for Clinical Research Training (ACRT)
1500 Sunday Drive, Suite 102
Raleigh, NC 27607**

**Association for Patient-Oriented Research (APOR)
4266 Bell Road, Suite 10
Newburgh, IN 47630**

**Clinical Research Forum (CR Forum)
1350 Connecticut Avenue NW, Suite 850
Washington, DC 20036**

**Society for Clinical and Translational Research (SCTS)
2025 M Street, NW, Suite 800
Washington, DC 20036**

Regarding Fiscal Year 2011 Appropriations for Clinical and Translational Research

**Submitted to the
House Committee on Appropriations; Subcommittee on Labor, Health and Human
Services, Education and Related Agencies**

April 16, 2010

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2011:

- 1) Provide full funding for the Clinical and Translational Science Awards (CTSA) Program at the National Institutes of Health (NIH) by providing \$700 million in support.**
- 2) Provide continued support for the K-Awards at NIH and AHRQ for the training and career development of research scientists.**
- 3) Provide continued support for comparative effectiveness research (CER) conducted at NIH and the Agency for Healthcare Research and Quality (AHRQ).**

The Association for Clinical Research Training (ACRT), the Association for Patient-Oriented Research (APOR), the Clinical Research Forum (CR Forum), and the Society for Clinical and Translational Science (SCTS) represent a coalition of professional organizations dedicated to improving the health of the public through increased clinical and translational research, and clinical research training. United by the shared priorities of the clinical and translational research community, ACRT, APOR, CR Forum, and SCTS advocate for increased clinical and translational research at the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ), and other federal science agencies.

On behalf of the Joint Advocacy Coalition of ACRT, APOR, CR Forum, and SCTS, I would like to thank the Subcommittee for their continued support of clinical and translational research, and clinical research training. The creation of the Patient-Centered Outcomes Research Institute in recent healthcare reform legislation will provide a much-needed and greatly appreciated boost to comparative effectiveness research (CER) at the federal level. As outlined by NIH Director Dr. Frances Collins in his five priorities for NIH, the translation of basic science to clinical treatment is an integral component to biomedical research today.

Today, I would like to address a number of related issues that cut to the heart of priorities for the clinical and translational research community including the CTSA program at NIH, career development for clinical researchers, and support for CER at the federal level.

As our nation's investment in biomedical research expands to provide more accurate and efficient treatments for patients, we must continue to focus on the translation of basic science to clinical research. The CTSA program at NIH is quickly becoming an invaluable resource in this area, but full funding is needed if we are to truly take advantage of this infrastructure.

1) Fully Funding and Support for the CTSA Program at NIH

With its establishment in 2006, the CTSA program at NIH began to address the need for increased focus on translational research, or research that bridges the gap between basic science discoveries and the bedside. Originally envisioned as a consortium of 60 academic institutions, the CTSA program currently funding 46 medical research institutions nationwide, and is set to expand to the full 60 by 2012. The CTSA's have an explicit goal of improving healthcare in the United States by transforming the biomedical research enterprise to become more effectively translational. Specifically, the CTSA program hopes to 1) improve the way biomedical research is conducted across the country; 2) reduce the time it takes for laboratory discoveries to become treatments for patients; 3) engage communities in clinical research efforts; 4) increase training and development in the next generation of clinical and translational researchers; and 5) accelerate T1 translational science.

Although the promise of the CTSA program is recognized both nationally and internationally, it has suffered from a lack of proper funding along with NIH, and the National Center for Research Resources (NCRR). In 2006, 16 initial CTSA's were funded, followed by an additional 12 in 2007 and 14 in 2008. Level-funding at NIH curtailed the growth of the CTSA's, preventing recipient institutions from fully implementing their programs and causing them to

drastically alter their budgets. If budgets continue to decline, the CTSAs risk jeopardizing not only new research but also the research begun by first, second, and third generation CTSAs.

We recognize the difficult economic situation our country is currently experiencing, and greatly appreciate the commitment to healthcare Congress has demonstrated with stimulus funding and through the fiscal year 2010 appropriations process. The CTSAs are currently funding 46 academic research institutions nation-wide at a level of \$474 million, with the goal of full implementation by 2012. In order to reach full implementation of 60 CTSAs by 2012, and to realize the promise of the CTSAs in transforming biomedical research in this nation to improve its impact on health, it is imperative that the CTSA program receive funding at the level of \$700 million in fiscal year 2011. Without full funding, more CTSAs will be expected to operate with fewer resources, curtailing their transformative promise.

It is our recommendation that the Subcommittee support full implementation of the CTSA program by providing \$700 million in FY 2011.

2) Continuing Support for Research Training and Career Development Programs Through the K Awards

The future of our nation's biomedical research enterprise relies heavily on the maintenance and continued recruitment of promising young investigators. Clinical investigators have long been considered an "endangered species", as financial barriers push medical students away from research. This trend must be arrested if we are to continue our pursuits of better treatments and cures for patients.

The K Awards at NIH and AHRQ provide much-needed support for the development of young investigators. As clinical and translational medicine takes on increasing importance, there is a great need to grow these programs, not reduce them. Career development grants are crucial to the recruitment of promising young investigators, as well as to the continuing education of established investigators. Reduced commitment to the K-12, K-23, K-24, and K-30 awards would have a devastating impact on our pool of highly trained clinical researchers. Even with the full implementation of the CTSA program, it will be critical for institutions without CTSAs to be able to retain their K-30 Clinical Research Curriculum Awards, as the K-30s remain a highly cost-effective method of ensuring quality clinical research training. ACRT, APOR, CRF, and SCTS strongly support the ongoing commitment to clinical research training through K Awards at NIH and AHRQ.

We ask the Subcommittee to continue their support for clinical research training and career development through the K Awards at NIH and AHRQ, in order to promote and encourage investigators working to transform biomedical science.

3) Continuing Support for CER

Comparative effectiveness research or "CER" emerged at the forefront of the healthcare reform debate, capturing the interest of both lawmakers and the American people. CER is the evaluation of the impact of different options that are available for treating a given medical condition for a particular set of patients. This broad definition can include medications, behavioral therapies, and

medical devices among other interventions, and is an important facet of evidence-based medicine. On behalf of ACRT, APOR, CR Forum, and SCTS, I would like to Congress for the creation of the Patient-Centered Outcomes Research Institute in the *Patient Protection and Affordable Care Act*, as well as the \$1.1 billion included for CER at NIH and AHRQ in the *American Recovery and Reinvestment Act (ARRA)*. Both AHRQ and NIH have long histories of supporting CER, and the standards for research instituted by American organizations like NIH and AHRQ serve as models for best practices worldwide. Not only are these agencies experienced in CER, they are universally recognized as impartial and honest brokers of information.

We are pleased that Congress recognizes the importance of these activities and believe that the peer review processes and infrastructure in place at NIH and AHRQ ensure the highest quality CER. We believe that collaboration between the Patient-Centered Outcomes Research Institute, NIH, and AHRQ will motivate all federal CER efforts. In addition to support for the CTSA program at NIH, we encourage the Subcommittee to include continued support for *Patient-Centered Health Research* at AHRQ, at a level of \$286 million, an increase of \$261 million over fiscal year 2009.

Thank you for the opportunity to present the views and recommendations of the clinical research training community. On behalf of ACRT, APOR, CR Forum, and SCTS, I would be happy to be of assistance as the process moved forward.

Statement of Albert F. Brandel on behalf of Lions Clubs International
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Lions Clubs International Foundation – Labor, HHS, Education Priorities 2010

**Statement of Al Brandel
Chairperson, Lions Clubs International Foundation
Immediate Past International President, Lions Clubs International**

Before the U.S. House Subcommittee on Labor, HHS, Education, and Related Agencies

April 13, 2010

I would like to begin by thanking Chairman David Obey, Ranking Member Todd Tiahrt and members of this distinguished Committee for the opportunity to provide this testimony on spending priorities before the Labor, HHS, Education, and Related Agencies Subcommittee. I would also like to congratulate you, Mr. Chairman, and your colleagues, for examining the way service organizations can collaborate with the Federal government in meeting pressing community needs for improved health and education services.

Lions Clubs International represents the largest and most effective NGO service organization presence in the world. Awarded and recognized as the # 1 NGO organization for partnership globally by The Financial Times 2007, Lions Clubs International also holds the highest four star (highest) rating from the CharityNavigator.com (an independent review organization). Lions and its official charity arm, Lions Clubs International Foundation (LCIF), have been world leaders in serving the vision, hearing, youth development, and disability needs of millions of people in America and around the world, and we work closely with other NGOs such as Special Olympics International to accomplish our common service goals. Since LCIF was founded in 1968, it has awarded more than 9,000 grants, totaling more than US \$640 million for service projects ranging from affordable hearing aids to diabetes-prevention. All Administrative costs are paid for through interest earned on investments, allowing LCIF to maximize out impact on the community and demonstrating the motto "We Serve."

Soon after its founding in Chicago in 1917, Lions Clubs became a service-oriented "export" to the World. Our current 1.3 million-member global membership, representing over 200 countries, serves communities through the following ways: protect and preserve sight; provide disaster relief; combat disability; promote health; and serve youth. The 14,000 individual Lions Clubs representing 400,000 individual citizens in North America are constantly expanding to add new programs its volunteers are working to bring health services to as many communities as possible.

Some of our major collaborative partners include: Habitat for Humanity, Special Olympics, the U.S. National Eye Institute, CADCA (Community Anti-Drug Coalition of America), Service Nation and many others.

Today, we face many complex challenges in the health and education sector, from preventable diseases that cause blindness in children to bullying, violence, and drug use among school-aged children. I will offer a brief summary of my remarks through an overview of where Lions Clubs International is involved in programs under the general jurisdiction of the Labor-HHS-Education Subcommittee, and where we recommend areas where Federal partnerships should be maintained and strengthened.

I. Health and Human Services

Domestic Sight Services

Thought our network of foundations and programs across America, Lions remains the single largest provider of charitable vision care, eyeglasses and hearing care services to needy and indigent people. Some of our major sight initiatives include:

- The Sight for Kids Program in collaboration with Johnson and Johnson. The program has provided 6 million vision screenings and eye-health education programs for children.
- Core 4 Preschool Vision Screening program enables Lions to conduct screenings for children in preschools. The program strives to deliver early detection and treatment for the most common vision disorders that can lead to amblyopia or “lazy eye.” LCIF has also provided grants and services to those affected by eye conditions that cannot be improved medically.
- Last August Lions Clubs sponsored “United We Serve Health Week” Signature Events around the country. These Health Week efforts, in conjunction with the White House, were effective in bringing awareness to vision health issues.

Vision Health Recommendations

Last year, the House overwhelmingly passed H.R. 577, the Vision Care for Kids Act, a bill that provides for comprehensive eye examinations to eligible children who have been screened, and to provide treatment or services to these children. Lions Clubs International supports efforts by Congress to expand vision screening services and eye health education programs for kids across the United States. These programs are crucial to early detection and treatment of disorders that lead to amblyopia or “lazy eye,” glaucoma, and diabetes-related blindness.

Our network of clubs, foundations and institutions continue to supplement public health efforts in this area through free vision screenings, fittings for eyeglasses, free prescription eyeglasses, and health education programs.

The Lions eye-screening program for our youngest and most vulnerable citizens has potential to expand output with the securing of significant support from policymakers in states and districts with strong Lions Club participation. This is particularly relevant in providing mobile eye screening programs for glaucoma and amblyopia treatment and follow up services in areas that are economically disadvantaged and include high-risk urban and rural populations.

There is recent Congressional support for the continuation and expansion of collaborative efforts between the Office of Head Start and stakeholders to ensure that all Head Start enrollees receive vision screening services and other resources available to them in their community. This is an effective means of ensuring that Congressionally-directed funding serve the communities where mobile screening units and preschool testing is most needed in a cost-effective manner. Again, for many localities in need of screening services, there is ample opportunity to expand comprehensive vision screening services so that no children are “left to fall through the cracks.”

Special Olympics “Healthy Athletes” Program

Lions Clubs International is a central part of a global team of health-care volunteers who participate in the Special Olympics Healthy Athletes program. The Opening Eyes program is a vision and eye health screening program that has provided some 100,000 vision screenings for Special Olympic Athletes. More than 40,000 Special Olympic athletes have received free prescription eyeglasses to date.

Lions supports further Congressional funding for “Healthy Athletes” and its crucial mission to: improve access and health care for Special Olympics athletes; make referrals to local health practitioners when appropriate; train health care professionals and students about the needs and care of people with intellectual disabilities; collect, analyze and disseminate data on the health status and needs of people with intellectual disabilities; and advocate for improved health policies and programs for people with intellectual disabilities.

Lions Affordable Hearing Aid Project (AHAP)

Lions Clubs International is committed to fighting hearing loss as well as blindness. By listening to community health organizations across the country, Lions Clubs International and their volunteer members became aware of the lack of quality and affordable hearing care, especially for people with incomes below or at 200% of the poverty level. Many people have been unable to access other personal and family resources to purchase hearing aids, and have been denied state and federal assistance. Lions Clubs 14 centers have been working to expand output in this area as demand continues to rise with a network of mobile health units and community based programs that screen more than two million people each year and provide hearing aids to 14,000 low income patients.

The statistics are unacceptable: 31 million persons in the United States experience some form of hearing loss, yet only 7.3 million opt to use hearing aids. According to audiology researchers, the market penetration for hearing aids is about 23.6%. For every four patients that enter a practice needing hearing aids, only one will purchase them. The median price tag is \$1900 (2005) for a digital hearing aid and prices go as high as \$4000. State Foundations, public health departments, and aging departments are in need of assistance in this area.

With the recent 25-30% increase in people seeking assistance for hearing aids, there is an immediate public imperative to address the problem. Federal dollars are stretched, but Federal support in this area would have significant public health dividends in difficult economic times.

II. “Lions Quest”/Education/Health Programs

Lions Clubs International's youth development initiatives, known collectively as “Lions Quest,” have been a prominent part of school-based K-12 programs since 1984. Fulfilling its mission to teach responsible decision-making, effective communications and drug prevention, Lions Quest has been involved in training more than 350,000 educators and other adults to provide services for over 11 million youth in programs covering 43 states. LCIF currently invests more than \$2 million annually in supporting life skills training and service learning, and that funding is matched by local Lions, schools and other partners.

Lions Quest curricula incorporate parent and community involvement in the development of health and responsible young people in the areas of: life skills development (social and emotional learning), character education, drug prevention, service learning, and bullying prevention. There is even a physical fitness component to this program that can assist Federal goals of reducing obesity in school-aged children.

These Lions Quest programs provide strong evidence of decreased drug use, improved responsibility for students own behavior, as well as stronger decision-making skills and test scores in math and reading. In August 2002, Lions Quest received the highest “Select” ranking from the

University of Illinois at Chicago-based Collaborative for Academic, Social and Emotional Learning (CASEL) for meeting standards in life skills education, evidence of effectiveness and exemplary professional development.

Lions Quest has extensive experience with Federal programs. Lions Quest Skills for Adolescence received a “Promising Program” rating from the U.S. Department of Education Safe and Drug Free Schools and a “Model” rating from the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA).

Lions Quest also has extensive experience of partnering with state service commissions to reach more schools and engage more young people in service learning. Successful partnerships have been active in Michigan, New York, Oklahoma, Tennessee and West Virginia with progress being made in Texas and Ohio.

Service Learning Initiatives

Lions Quest has also pursued Learn and Serve Grant funding to support implementation of Lions Quest programming in several states. We strongly support Congressional efforts to fund the Edward M. Kennedy Serve America Act that was signed into law one year ago. The Serve America Act authorizes the Corporation for National and Community Service to expand existing programs and add several new programs and initiatives to provide service learning school-based programs for students as well as Innovative and Community-Based Service-Learning Programs and Research. Another program of value that was authorized by the Edward M. Kennedy Act is the Social Innovation Fund that provides growth capital and other support so that the most effective programs can be identified.

Social and Emotional Learning Programs

In addition, Lions Clubs recommends Congressional support for social and emotional learning (SEL) programs that stimulate growth among schools nationwide through distribution of materials and teacher training, and to create opportunities for youth to participate in activities that increase their social and emotional skills. Not only do SEL curricula contribute to the social and emotional development of youth, but they also provide invaluable support to students' school success, health, well-being, peer and family relationships, and citizenship. While still conducting scientific research and reviewing the best available science evidence, over time Lions Clubs and its SEL partners have increasingly worked to provide SEL practitioners, trainers and school administrators with the guidelines, tools, informational resources, policies, training, and support they need to improve and expand SEL programming.

Overall, SEL training programs and curricula have outstanding benefits for school-aged children:

- SEL *prevents* a variety of problems such as alcohol and drug use, violence, truancy, and bullying. SEL programs for urban youth emphasize the importance of cooperation and teamwork.
- Positive outcomes increase in students who are involved in social and emotional learning programming by an average of *11 percentile points* over other students.

- With greater social and emotional desire to learn and commit to schoolwork, participants benefit from improved attendance, graduation rates, grades, and test scores. Students become caring, concerned members of their communities.

Conclusion

Lions Clubs remains committed to domestic activities such as major sight initiatives and positive youth development and youth service programs. Today we face great health and educational challenges, and Lions Clubs International understands the importance not only of community service but of instilling those among members of our next generation. The success of non-profit entities such as Lions Clubs show what the service sector can do for economic and social development of communities that are especially hard hit by the recession, and we are committed to forming more effective alliances and partnerships to increase our domestic impact. We look forward to working with you and your colleagues on taking up these important challenges.

About Albert F. Brandel

Albert F. Brandel of Metulle, New York, is the Immediate Past President of the International Association of Lions Clubs and Chairman of the Lions Clubs International Foundation. He is a retired police detective. For many years he investigated child abuse and neglect, juvenile delinquency, domestic violence involving children and missing children.

A member of the West Hempstead Lions Club since 1975 and an associate member of the Metulle Lions Club, Past International President Brandel has held many offices in the association, including club president, district governor and international director. He has also served as a presenter and panelist at USA/Canada Lions Leadership Forums. He worked with the Long Island Lions Eye Bank as a transporter and has been the Lions Representative to UNICEF in New York for 10 years. He helped coordinate Lions relief efforts at the World Trade Center following September 11, 2001.

Testimony on Behalf of **March of Dimes Foundation**

Committee on Appropriations - Subcommittee on Labor, Health and Human Services and Education

The 3 million volunteers and 1,400 staff members of the March of Dimes Foundation appreciate the opportunity to submit the Foundation's federal funding recommendations for Fiscal Year 2011 (FY11). The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to support research and services related to polio. Today, the Foundation works to improve the health of women, infants and children by preventing birth defects, premature birth and infant mortality through research, community services, education and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with 51 chapters and 213 divisions in every state, the District of Columbia and Puerto Rico. Additionally, in 1998, March of Dimes established its Global Programs to extend its mission overseas through partnerships with countries to deliver interventions directed at reducing birth defects and preterm birth.

The March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in the future of health of the nation's children.

Preterm Birth

According to a 2009 report from the National Center for Health Statistics (NCHS), the primary reason for the higher infant mortality rate in the United States compared to European nations is the greater percentage of preterm births—12.4 percent in U.S. compared to 6.3 percent in Sweden. This suggests that preterm birth prevention is central to lowering the U.S. infant mortality rate. Moreover, the Institute of Medicine estimated that preterm birth cost the United States more than \$26 billion in 2005, with costs continuing to climb each year.

In June of 2008, the U.S. Surgeon General sponsored a conference to develop a research agenda to address the costly and serious problem of preterm birth. More than 200 of the country's foremost researchers, representing a diversity of backgrounds and expertise, met for two days and created an action plan of needed steps. Within these steps, there are several cross-cutting themes including recommendations to enhance biomedical and epidemiological research and to strengthen our nation's vital statistics program. The March of Dimes funding requests enumerated below are based on the recommendations of the Surgeon General's Conference.

National Institutes of Health - Office of the Director

The March of Dimes commends members of the Committee for supporting the National Children's Study (NCS) by including \$193.8 million in the FY10 Consolidated Appropriations Act. **For FY11, the Foundation supports the President's funding recommendation and urges the Subcommittee to maintain its commitment to this vital study by providing \$194.4 million.** Currently in the pilot phase, the NCS is tracking the more than 150 children born to study participants. The data from this important effort will inform the work of scientists in universities and research organizations across the nation and around the world, helping them identify precursors to disease and to develop new strategies for prevention and treatment. The first data generated by the NCS will provide information concerning disorders of birth and infancy including preterm birth and its health consequences. The Foundation remains committed

to supporting a well designed NCS that promotes research of the very highest quality.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
The March of Dimes recommends a funding increase of at least 12.5 percent for NICHD in FY11. This increase in funding will enable NICHD to maintain the momentum and investments made with support provided through the Recovery Act. It will also enable the Institute to expand its support for preterm birth-related research and to initiate establishment of a network of integrated transdisciplinary research centers as recommended by the Institute of Medicine and the experts who participated in the Surgeon General's Conference. The causes of preterm birth are multi-factorial and necessitate a collaborative approach integrating many disciplines. These new centers would serve as a national resource for investigators to design and to share new research approaches and strategies to comprehensively address the problems of preterm birth.

Centers for Disease Control and Prevention - Preterm Birth

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health. In 2009, CDC created a robust research agenda to prevent preterm birth by improving national and state data to track preterm births; developing, implementing and evaluating methods for prevention; understanding the problem of late preterm birth; and conducting etiologic and epidemiologic studies of early preterm birth. **For FY11, the March of Dimes recommends a \$6 million increase in the preterm birth line to strengthen national data systems and to expand research on very early as well as late preterm births as authorized by the PREEMIE Act (P.L. 109-450).**

Centers for Disease Control and Prevention - National Center for Health Statistics

The National Center for Health Statistics (NCHS) national vital statistics program collects birth data that is used to monitor the nation's health status, set priorities and evaluate health programs. It is imperative that data collected by NCHS is comprehensive and timely. Currently, only 75 percent of states and territories use the 2003 birth certificate format and only 65 percent have adopted the 2003 death certificate. **Consistent with the President's Budget request, the Foundation recommends allocating \$11 million specifically to the National Vital Statistics System to help support modernization of the state and territorial vital statistics infrastructure without undermining the scope and quality of data collected nationally.**

Health Resources and Services Administration - Healthy Start

The Healthy Start Initiative is a collection of community-based projects focused on reducing infant mortality, low birthweight and racial disparities in perinatal outcomes. Communities with Healthy Start programs have seen significant improvements in health outcomes; therefore **the March of Dimes recommends a funding level for these projects of \$120 million in FY11.**

Birth Defects

An estimated 120,000 infants in the U.S. are born with birth defects each year. Genetic or environmental factors, or a combination, can cause a birth defect; however, the causes of 70 percent of birth defects remain unknown. Investing additional federal resources in research to unveil the causes and prevent, or reduce, the incidence of birth defects is sorely needed.

CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD)

The NCBDDD conducts programs to protect and improve the health of children by preventing birth defects and developmental disabilities and by promoting optimal development and wellness among children with disabilities. For FY11, the March of Dimes requests an **overall funding level of \$163 million, a \$20 million increase over FY10, for NCBDDD. Within that increase, we encourage the committee to allocate \$5 million for support of birth defects research and surveillance and an additional \$2 million for folic acid education.** This is a sound public health investment that will promote wellness and prevention, reduce health disparities, support the creation of new educational materials for consumers and their families and will enable CDC to better facilitate transition to adulthood for children with disabilities.

Sustaining the investment in the National Birth Defects Prevention Study—the largest case-controlled study of birth defects ever conducted—is needed to support genetic analysis of the samples already obtained. In 2009, CDC educated health care providers through the dissemination of more than 10 reports which resulted from this Study. Among the topics were the risk factors for birth defects such as maternal smoking, obesity and antidepressant use during pregnancy.

NCBDDD also supports state-based birth defects tracking systems and programs to prevent and treat affected children. Surveillance forms the backbone of a vital, functional and responsive public health network. Due to current the current fiscal crises being faced by many states, funding for some of these systems is in jeopardy. Increased investment from the federal government is necessary to ensure continued investment in birth defects surveillance programs.

Finally, NCBDDD is conducting a national education campaign aimed at increasing the number of women consuming appropriate amounts of folic acid. CDC estimates that up to 70 percent of neural tube defects could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily. To achieve the full prevention potential of folic acid, CDC's national public and health professions education campaign must be expanded.

Newborn Screening

Newborn screening is a vital public health activity used to identify and treat genetic, metabolic, hormonal and functional disorders in newborns. Screening detects conditions in newborns that, if left untreated, can cause disability, mental retardation, serious illness or even death. Across the nation, state and local governments are experiencing significant budget shortfalls; due to this fiscal pressure, newborn screening programs are threatened by funding cuts. While the ramifications—such as discontinuing screening for certain conditions or postponing the purchase of necessary technology—can vary by state, any funding cut in this essential program puts infants at risk for permanent disability or even death. An additional **\$5 million for HRSA's heritable disorders program, as authorized by the Newborn Screening Saves Lives Act (P.L. 110-204)**, is necessary to increase support for state efforts to upgrade existing programs, to acquire state-of-the-art technology and to increase capacity to reach and educate health professionals and parents on newborn screening programs and follow-up services.

Other**Agency for Health Research and Quality (AHRQ)**

AHRQ supports research to improve health care quality, reduce costs and broaden access to essential health services. **The Foundation recommends \$611 million** for AHRQ to continue its important work and support priority initiatives, including the development and dissemination of maternal and pediatric quality measures and comparative effectiveness research. Moreover, with the historic enactment of health reform, AHRQ's research is needed more than ever to build the evidence-base to improve health and health care coverage.

Health Resources and Services Administration - Maternal and Child Health Block Grant

Title V of the Social Security Act, the Maternal and Child Health (MCH) Block Grant, supports a growing number of community-based programs (e.g., home visiting, respite care for children with special health care needs and supplementary services for pregnant women and children enrolled in Medicaid and the State Children's Health Insurance Program), but federal support has not kept pace with increased enrollment and demand for services. **The March of Dimes recommends funding the MCH Block Grant at the level of \$730 million.**

CDC National Immunization Program

Infants are particularly vulnerable to infectious diseases, which is why it is critical to protect them through immunization. In 2008, the national estimated immunization coverage among children 19-35 months of age was 76.1 percent. The CDC National Immunization Program supports states, communities and territorial public health agencies through grants to reduce the incidence of disability and death resulting from vaccine-preventable diseases. **The March of Dimes recommends \$865.6 million for FY11** and urges the subcommittee to continue its longstanding policy of strong support for federal vaccine programs.

CDC Polio Eradication

Since its creation as an organization dedicated to research and services related to polio, the March of Dimes has been committed to the eradication of this disabling disease. **For FY11, the Foundation recommends a funding level of \$102 million for the CDC global polio eradication program.** Level with FY10, this funding would allow CDC to continue its supplementary immunization activities in the remaining endemic and high-risk countries in Africa and Asia and to quickly respond in order to interrupt polio transmission in these regions.

Closing

Thank you for the opportunity to testify on the federally supported programs of highest priority to the March of Dimes. The Foundation's volunteers and staff in every state, the District of Columbia and Puerto Rico look forward to working with Members of the Subcommittee to secure the resources needed to improve the health of the nation's mothers, infants and children.

**MARCH OF DIMES
FY2011 FEDERAL FUNDING PRIORITIES
(Dollars in Millions)**

| PROGRAM | FY 2010 FUNDING | MARCH OF DIMES REC |
|---|--------------------|--------------------------|
| National Institutes of Health (Total) | 31,089 | 35,000 |
| National Children's Study | 193.8 | 194.4 |
| Common Fund | 544 | 612 |
| National Institute of Child Health and Human Development | 1,329 | 1,495 |
| National Human Genome Research Institute | 516 | 581 |
| National Center on Minority Health and Disparities | 212 | 239 |
| Centers for Disease Control and Prevention (Total) | 6,475 | 8,800 |
| Birth Defects Research & Surveillance | 21,342 | 26,342 |
| Folic Acid Campaign | 3.1 | 5.1 |
| Immunization | 562 | 865.6 |
| Polio Eradication | 102 | 102 |
| Preterm Birth | 2 | 8 |
| | 139 | 162 |
| National Center for Health Statistics | | |
| Health Resources and Services Administration (Total) | 7,483 | 9,150 |
| Maternal and Child Health Block Grant | 662 | 730 |
| Newborn Screening | 10 | 15 |
| Newborn Hearing Screening | 19 | 19 |
| Consolidated (Community) Health Centers | 2,146 | 2,560 |
| Healthy Start | 105 | 120 |
| Agency for Healthcare Research and Quality | 397 | 611 |



**STATEMENT OF
HOPE BARTON
ASSOCIATE, UNIVERSITY LIBRARIAN, SERVICES
UNIVERSITY OF IOWA LIBRARIES**

**ON BEHALF OF THE
MEDICAL LIBRARY ASSOCIATION
AND THE
ASSOCIATION FOR ACADEMIC HEALTH SCIENCES LIBRARIES
507 CAPITOL COURT, NE, SUITE 200
WASHINGTON, DC 20002
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**REGARDING FISCAL YEAR 2011 APPROPRIATIONS FOR THE
NATIONAL INSTITUTES OF HEALTH'S
NATIONAL LIBRARY OF MEDICINE**

**SUBMITTED TO THE
HOUSE COMMITTEE ON APPROPRIATION'S SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED
AGENCIES**

FRIDAY, APRIL 16, 2010

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2011:

- 1) CONTINUE THE COMMITMENT TO THE NATIONAL INSTITUTES OF HEALTH (NIH) AND THE NATIONAL LIBRARY OF MEDICINE (NLM) BY INCREASING FUNDING LEVELS 12% TO \$35 BILLION FOR NIH AND \$402 MILLION FOR NLM**
- 2) CONTINUE TO SUPPORT THE NIH PUBLIC ACCESS POLICY, WHICH REQUIRES THAT ALL FINAL, PEER-REVIEWED MANUSCRIPTS ARE MADE AVAILABLE THROUGH NLM'S PUBMED CENTRAL DATABASE WITHIN 12 MONTHS OF PUBLICATION AND SUPPORT THE ESTABLISHMENT OF SIMILAR POLICIES IN OTHER FEDERAL AGENCIES**
- 3) CONTINUE TO SUPPORT THE MEDICAL LIBRARY COMMUNITY'S IMPORTANT ROLE IN NLM'S OUTREACH, TELEMEDICINE, DISASTER PREPAREDNESS AND HEALTH INFORMATION**

TECHNOLOGY (HEALTH IT) INITIATIVES AND THE IMPLEMENTATION OF HEALTH CARE REFORM.

On behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL), thank you for the opportunity to present testimony regarding FY 2011 appropriations for the National Library of Medicine (NLM).

MLA is a nonprofit, educational organization with more than 4,000 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the health care community and the public.

AAHSL is comprised of the directors of the libraries of 142 accredited American and Canadian medical schools belonging to the Association of American Medical Colleges (AAMC). AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health professionals is trained in information-seeking skills that enhance the quality of healthcare delivery.

Together, MLA and AAHSL address health information issues and legislative matters of importance through a joint legislative task force and a Government Relations Committee.

1. THE IMPORTANCE OF ANNUAL FUNDING INCREASES FOR NLM.

We are pleased that the FY 2010 Appropriations package contained funding increases for NIH and NLM and bolstered their baseline budgets. We encourage the Subcommittee to continue to provide meaningful annual increases for NIH and NLM in the coming years, and recommend a 12% increase for FY 2011.

Recovery funding and the FY 2010 budget increases stimulated the economy and biomedical research. In the case of NLM, Recovery Act funding allowed timely and much-needed increases in support for leading edge research and training in biomedical informatics—the kinds of programs that will influence future developments in health information technology. In FY 2011 and beyond, it will be critical to augment NLM's baseline budget to accommodate expansion of its information resources, services, and programs, which must collect, organize, and make accessible rapidly expanding volumes of biomedical knowledge, including the influx of data from high-throughput genome sequencing systems and genome-wide association studies. Increased funding will also position NLM to strengthen its contributions to successful implementation of recent Congressional priorities related to health care reform, health information technology, drug safety through its efforts to: enhance access to the results of comparative effectiveness research, maintain and disseminate health information technology standards, and to expand its clinical trial registry and results database in response to legislative requirements.

GROWING DEMAND FOR NLM'S BASIC SERVICES

As the world's foremost digital library and knowledge repository in the health sciences, NLM provides the critical infrastructure in the form of data repositories and online integrated services, such as GenBank and PubMed, that are helping to revolutionize medicine and advance science to the next important era which includes individualized medicine based on an individual's unique genetic differences. PubMed, with more than 20 million citations to the biomedical literature, is the world's most heavily used source of information about published results of biomedical research, and GenBank, with its international partners, has become the definitive source of gene sequence information. Their content continues to grow, as does their usage by medical librarians, biomedical researchers, clinicians, students, and the public. New resources, such as the Sequence Read Archive and database of Genotypes and Phenotypes enable NLM to collect, organize, and make available for research the incredible volumes of data flowing from high-throughput genome sequencing machines and from genome wide association studies that aim to link genetic variations to specific diseases and conditions.

As the world's largest and most comprehensive medical library, services based on NLM's traditional and electronic collections continue to steadily increase each year. These collections stand at more than 11.4 million items-books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health science information in all formats, NLM is ensuring the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and ensuring that each citizen can make the best, most informed decisions about their healthcare. Without NLM our nation's medical libraries would be unable to provide the quality information services that our nation's health professionals, educators, researchers and patients have come to expect.

2. SUPPORT AND EXTEND PUBLIC ACCESS

The Appropriations Committee has shown unprecedented foresight and leadership by using the annual spending bills as the vehicle to establish a mandatory public access policy at the NIH. This highly beneficial policy, which requires all NIH-funded researchers to deposit their final, peer-reviewed manuscripts in NLM's PubMed Central database within 12 months of publication, is improving access to timely and relevant scientific information, stimulating discovery, informing clinical care, and improving public health literacy. We ask the Committee to remain a strong voice in support of the NIH policy, and to support the extension of public access policies to other federal science and education agencies. MLA and AAHSL strongly support the expansion of public access policies to other agencies, because it would bring the benefits of public access to other fields of research and because research in other fields is increasingly relevant to biomedicine.

3. SUPPORT AND ENCOURAGE NLM PARTNERSHIPS WITH THE MEDICAL LIBRARY COMMUNITY.

Outreach and Education

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities are designed to educate medical librarians, health professionals and the general

public about NLM's services and to train them in the most effective use of these services. NLM has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. Furthermore, NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. One example of NLM's leadership is the "Partners in Information Access" program, which is designed to improve the access of local public health officials to information needed to prevent, identify and respond to public health threats. With nearly 6,000 members in communities across the country, the National Network of Libraries of Medicine (NNLM) is well positioned to ensure that every public health worker has electronic health information services that can protect the public's health.

NLM is also at the forefront of efforts to provide consumers with trusted, reliable health information. With help from Congress, NLM, NIH and the Friends of NLM, launched NIH *MedlinePlus Magazine* in September 2006. This quarterly publication is distributed in doctors' waiting rooms, and provides the public with access to high quality, easily understood health information. Its readership is now estimated at 5 million people nationwide and is poised to grow thanks to the launch of a Spanish/English version, *NIH MedlinePlus Salud* in January 2009. NLM also continues to work with medical librarians and health professionals to encourage doctors to provide MedlinePlus "information prescriptions" to their patients, directing them to relevant information on NLM's consumer-oriented MedlinePlus information system. This initiative also encourages genetics counselors to prescribe the use of NLM's Genetic Home Reference website. A growing number of clinical care organizations are implementing specific links to MedlinePlus from electronic health record systems as an effective way to provide patient-specific educational materials and to achieve an emerging criterion for achieving meaningful use of health IT.

NLM also provides access to information about clinical research. Launched in February of 2000, ClinicalTrials.gov lists more than 88,000 U.S. and international trials for a wide range of diseases. The clinical trials database is a free and invaluable resource to patients and families who are interested in participating in cutting-edge treatments for serious illnesses. In recent years, it has become an even more valuable resource for patients, clinicians, researchers, and others. In response to the Food and Drug Administration Amendments Act of 2007, NLM quickly expanded ClinicalTrials.gov to accept summary results of clinical trials, including adverse events. Such information is not available systematically from other publicly accessible resources, and all too often is not published in the scientific literature. As of April 2010, more than 1600 results records had been posted in the database, with more than 100 additional records being submitted each week.

MLA and AAHSL applaud the success of NLM's outreach initiatives, particularly those initiatives that reach out to medical libraries and health consumers. We ask the Committee to encourage NLM to continue to coordinate its outreach activities with the medical library community in FY 2011.

EMERGENCY PREPAREDNESS AND RESPONSE

MLA and AAHSL are pleased that NLM has established a Disaster Information Management Research Center to expand NLM's capacity to support disaster response and management initiatives, as recommended in the *NLM Board of Regents Long Range Plan for 2006-2016*. Presently, libraries are a significant, but underutilized resource for community disaster planning and management efforts, which NLM can help to deploy.

Following Hurricane Katrina, NLM worked with health sciences libraries across the country to provide health professionals and the public with access to needed health and environmental information by: 1) quickly compiling web pages on toxic chemicals and environmental concerns; 2) rapidly providing funds, computers and communication services to assist librarians in the field who were restoring health information services to displaced clinicians and patients; and 3) rerouting interlibrary loan requests from the afflicted regions through the NLM. More recently, in response to the earthquake in Haiti, NLM developed and posted a Health Resources for Haiti web page, within a week of the earthquake, with information in English and Haitian Creole. It also activated the emergency access initiative it had developed with libraries and American publishers to make available free full-text articles from hundreds of biomedical journals and reference books for medical teams responding to the disaster. NLM also deployed a system it had developed for use in the National Capitol Region to assist in reunifying family members who were separated during the earthquake, sharing information with other lost - person finder systems, such as those set up by Google, CNN, and the International Red Cross.

Such initiatives demonstrate the role that NLM can play in emergency preparedness and response. We ask the Subcommittee to show its support for this initiative, which has a major objective of ensuring continuous access to health information and effective use of libraries and librarians when disasters occur.

HEALTH IT AND BIOINFORMATICS

NLM has played a pivotal role in creating and nurturing the field of medical informatics, which is the intersection of information science, computer science and healthcare. Health informatics tools include computers, clinical guidelines, formal medical terminologies, and information and communication systems. For nearly 35 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including a variety of telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research programs at universities across the country. Many of the country's exemplary electronic and personal health record systems benefited from NLM grant support.

The importance of NLM's work in health IT continues to grow as the nation moves toward more interoperable health IT systems. A leader in supporting, licensing, developing and disseminating standard clinical terminologies for free US-wide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to promote the adoption of interoperable electronic records. It has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems.

MLA and AAHSL encourage the Subcommittee to continue their strong support of NLM's medical informatics and genomic science initiatives, at a point when the linking of clinical and genetic data holds increasing promise for enhancing the diagnosis and treatment of disease. MLA and AAHSL also supporting health information technology initiatives in ONCHIT and the Agency for Healthcare Research and Quality that build upon initiatives housed at NLM.

BUILDING AND FACILITY NEEDS

The tremendous growth in NLM's basic functions related to the acquisition, organization and preservation of an ever-expanding collection of biomedical literature, combined with its growing contributions to health care reform, health information technology, drug safety, and exploitation of genomic information is straining the Library's physical resources. NLM now houses 1,100 staff in a facility built to accommodate only 650. This increase in the volume of biomedical information and in the number of personnel has led to a serious space shortage. Digital archiving—once thought to be a solution to the problem of housing physical collections—has only added to the challenge, as materials must often be stored in multiple formats and as new digital resources consume increasing amounts of data center storage space. As a result, the space needed for computing facilities has also grown, further squeezing out staff. In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. Further, Senate Report 108-345 that accompanied the FY 2005 appropriations bill acknowledged that the design for the new research facility at NLM had been completed, and the Committee urged NIH to assign a high priority to this construction project so that the information-handling capabilities and biomedical research are not jeopardized.

MLA and AAHSL encourage the Subcommittee to continue its strong support of NLM's goals in order to strengthen the Library's ability to provide support for implementation of health care reform. At a time when medical and health science libraries across the nation face growing financial and space constraints, ensuring that NLM continues to serve as the archive of last resort for biomedical collections is critical to the medical library community and the public we serve.

Thank you for the opportunity to present the views of the medical library community.

**TESTIMONY OF WAYNE J. RILEY, M.D., M.P.H., MBA, FACP
PRESIDENT
AND
CHIEF EXECUTIVE OFFICER**

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PRESENTED BEFORE THE

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION AND RELATED AGENCIES**

SUMMARY OF FISCAL YEAR 2009 RECOMMENDATIONS:

- 1) **\$300 MILLION FOR THE TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS, INCLUDING:**
 - **\$33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**
 - **\$35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**
- 2) **\$250 MILLION FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES.**
- 3) **\$169 MILLION FOR THE NATIONAL CENTER FOR RESEARCH RESOURCES EXTRAMURAL FACILITIES CONSTRUCTION PROGRAM.**
 - a. **\$ 6.7% INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.**
 - b. **\$ 119 MILLION FOR EXTRAMURAL FACILITIES CONSTRUCTION.**
- 4) **\$65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH.**
- 5) **\$65 MILLION FOR THE DEPARTMENT OF EDUCATION'S STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS PROGRAM.**

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wayne J. Riley, President and CEO of Meharry Medical College in Nashville, Tennessee. I have previously served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine in Houston, Texas and as assistant chief of medicine and a practicing general internist at Houston's Ben Taub General Hospital. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our nation and evaluate our needs over the next ten years. I took you seriously and came here prepared to offer my best judgments. First, I want to say that it is clear that health disparities among various populations and across economic status are rampant and overwhelming. Over the next ten years, we will need to be able to deliver more culturally relevant and culturally competent healthcare services. Bringing healthcare delivery up to this higher standard can serve as our nation's own preventive healthcare agenda keeping us well positioned for the future.

Minority health professional institutions and the Title VII Health Professions Training programs address this critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our nation's most medically underserved communities. Our nation's health professions workforce does not accurately reflect the racial composition of our population. For example, African Americans represent approximately 15% of the U.S. population while only 2-3% of the nation's healthcare workforce is African American.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the federal government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. **Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.**

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 (FY06) and FY07 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities

for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my medical degree from Morehouse School of Medicine, a historically black medical school in Atlanta. I give credit to my career in academia, and my being here today, to Title VII Health Profession Training programs' Faculty Loan Repayment Program. Without that program, I would not be the president of my father's alma mater, Meharry Medical College, another historically black medical school dedicated to eliminating healthcare disparities through education, research and culturally relevant patient care.

Minority Centers of Excellence: COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. *For FY11, I recommend a funding level of \$33.6 million for COEs.*

Health Careers Opportunity Program (HCOP): HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. *For FY11, I recommend a funding level of \$35.6 million for HCOPs.*

NATIONAL INSTITUTES OF HEALTH (NIH): EXTRAMURAL FACILITIES

CONSTRUCTION--Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH over the past decade, it is critical that our nation's research infrastructure remain strong. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources is \$250 million. The law also includes a 25% set-aside for "Institutions of Emerging Excellence" (many of which are minority institutions) for funding up to \$50 million. Finally, the law allows the NCCR Director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation because they are necessary for our minority health professions training schools. *In FY11, please fund this program at least at \$50 million.*

RESEARCH CENTERS IN MINORITY INSTITUTIONS: The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. *Therefore, the funding for this important program grow at the same rate as NIH overall in FY11.*

STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS -

DEPARTMENT OF EDUCATION: The Department of Education's Strengthening Historically

Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In FY11, an appropriation of \$75 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

National Institute on Minority Health and Health Disparities: The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities. *For FY11, I recommend a funding level of \$500 million for the NIMHD.*

Department of Health and Human Services' Office of Minority Health: Specific programs at OMH include:

- 1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
- 2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
- 3) Supporting conferences for high school and undergraduate students to interest them in health careers, and
- 4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. *For FY11, I recommend a funding level of \$75 million for the OMH.*

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Meharry Medical College along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. Meharry and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have done for 1876.

Thank you, Mr. Chairman, for this opportunity.

STATEMENT BY THE
MENDED HEARTS, INCORPORATED
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FY 2011 APPROPRIATIONS FOR LABOR-HHS-EDUCATION
NATIONAL INSTITUTES OF HEALTH

I am Robert A. Scott, National Advocacy Chairman for Mended Hearts Inc., a national heart disease support group with more than 275 chapters across the United States and Canada. In 2009, accredited Mended Hearts volunteers visited 187,183 patients and families and are serving 430 hospitals throughout the United States.

As a walking testimony of the benefits of NIH-supported heart research, I would like to share my story with you. In 1998, at age forty-eight, I suffered my first heart attack while playing volleyball. While at Woonsocket, Rhode Island's Landmark Medical Center, doctors diagnosed me as suffering a so called silent heart attack. I learned that as many as 4 million Americans may experience this type of episode--a heart attack with no warning just like I had.

After being stabilized, I was transferred to Roger Williams Hospital, in Providence, Rhode Island for a heart catheterization—the gold standard for diagnosis of heart problems. The procedure showed that I had a blockage in my artery that required a stent to open it. Also, it showed that the lower chamber of my heart was damaged, resulting in congestive heart failure that could be controlled with medicine. A stent was inserted in my artery in Rhode Island Hospital.

In 1999, I received another heart catheterization in Miriam Hospital in Providence, Rhode Island because of the damage to my heart from the silent heart attack. However, this time, I was told that my artery could not be repaired with a stent and that I needed heart bypass surgery the next morning. Calling me a high risk patient because of my age and my weakened heart, my surgeon encouraged me to find a doctor in Boston because my heart might not start again. However, he assured me that if this happens they had a device that could keep me alive for only seven hours. Thank goodness, he told me that in Boston they had another device that could keep me alive for seven months while they located a replacement heart. In less than ten hours I went from the possibility of needing another stent, heart bypass surgery, and a heart transplant. My journey with heart disease continued.

My next stop was to visit my local cardiologist in Woonsocket who estimated my survival rate at 20%, but he thought I would make it. Thankfully, he was right and I survived heart bypass surgery.

But my journey didn't end there. My congestive heart failure was causing my heart to beat irregularly, so I received an implantable defibrillator to control the problem in 2002. However, this device had to be replaced in Rhode Island nearly four years later.

My story continues in 2007 where I started experiencing daily chest pain and shortness of breath. Yet another heart catheterization, showed that, I needed an additional stent, but this time in Miriam. After the procedure, the doctor told me the original heart bypass surgery was no longer effective. Although I was scared, my doctors comforted me by explaining that a new medical innovation could save my life—a drug eluting stent. My doctor explained that it could open up the original blockage from my silent heart attack. He added that if these state-of-the art stents had been available in 1998, I would not have had to have the heart bypass surgery.

Despite previous treatments, I once again was faced with cardiovascular disease in February of 2009. This time it was a stroke warning sign. While driving, I suddenly felt dizzy, so pulled my car over to stop. The next thing I knew, I had passed out for a very short time and felt numb on the right side of my face. This scared me enough that I drove myself to the hospital which just happened to be on the same street where I stopped my car. Upon arrival, I was a little confused and was later admitted into the hospital. The next day, my cardiologist told me I had a transient ischemic attack (TIA). My doctor said there was no need for a stress test and because of my heart condition I should have another cardiac catheterization. The catheterization showed that one of my arteries had minor blockage, so the doctor placed another stent in my artery. To date, I have not experienced another TIA.

Today, heart attack, stroke and other cardiovascular disease remain our Nation's most costly and No. 1 killer and a major cause of disability. Thanks to medical research supported by the NIH, I am alive today. I am concerned that NIH continues to invest only 4% of its budget on heart research and a mere 1% on stroke research when there are so many people in our country just like me. Enhanced NIH funding dedicated to heart and stroke research will bring us closer to a cure for these often deadly and disabling diseases.

**Dr. Larry Wright, President and CEO
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**Written Testimony for the House Appropriations Subcommittee on Labor, Health and
Human Services, Education and Related Agencies
March 23, 2010**

Chairman Obey and Ranking Member Tiahrt, I thank you for the opportunity on behalf of MENTOR/National Mentoring Partnership to submit written testimony in support of resources for youth being mentored or in need of a caring, screened, and trained mentor. Specifically, we ask your continued support for the:

- **Mentoring Children of Prisoners program**, and
- **Serve America Act programs** that support youth mentoring.

First, we thank you for previous support of the **U.S. Department of Health and Human Services' Mentoring Children of Prisoners** program and request that you include level funding for the program in FY 2011. MENTOR has appreciated the support of the Subcommittee in previous years, in funding this competitive grant program at roughly \$50 million since FY 2004. We applaud President Obama for including level funding in his FY 2011 Budget for this program at \$49.3 million.

This authorized program provides competitive grants to local mentoring organizations to help them match children of incarcerated parents with caring adult mentors. As noted by the Administration for Children and Families, Faith-Based and Community Initiative¹, more than two million children and youth in the U.S. have at least one parent in a federal or state correctional facility. Furthermore, the Initiative writes:

"In addition to experiencing disruption in the relationship with their parent, these young people often struggle with the economic, social, and emotional burdens of the incarceration. Data indicate that mentoring programs can help young people, including those with incarcerated parents, by reducing their first-time drug and alcohol use, improving their relationships and academic performance, and reducing the likelihood that they will initiate violence. In addition, mentoring programs can provide these children with opportunities to develop a trusting relationship with a supportive adult and a stable environment that can promote healthy values and strong families."

In addition, since 2007, MENTOR/National Mentoring Partnership has served as the administrator of the Mentoring Children of Prisoners: Caregiver's Choice voucher demonstration project (Federal Grant # 90CV0457). Caregiver's Choice allows caregivers and parents the opportunity to directly connect their children with quality mentoring programs. Programs that meet quality standards created by experts—in mentoring and working with families of the incarcerated—have been selected to take part. This three-year demonstration project has consistently met its goals.

¹ http://www.acf.hhs.gov/programs/fbci/progs/fbci_mcp.html

We ask for your continued support to ensure that the Department of Health and Human Services honors all mentoring relationships established between eligible children and enrolled programs under the Mentoring Children of Prisoners program.

Second, the mentoring field as a stream of service was provided a boost through the passage and enactment of the Edward M. Kennedy Serve America Act. We support **President Obama's FY 2011 Budget request for Serve America Act Programs under the Corporation for National and Community Service**. This includes \$914.3 million for AmeriCorps, \$60 million for the Social Innovation Fund, \$10 million for the Volunteer Generation Fund, \$40.2 million for Learn and Serve America, and \$221 for Senior Corps.

As enacted, the Serve America Act provides many more opportunities to support quality mentoring. For example, mentoring is an eligible activity for those engaged in the newly-expanded AmeriCorps, Volunteers In Service To America (VISTA) and Retired and Senior Volunteer Programs (RSVP), as well as the newly-created Education Corps and Veterans' Corps. In addition, *Mentoring Partnerships*, which support the expansion of quality mentoring in many states throughout the country, are now eligible for funding through the National Service Trust Program and Volunteer Generation Fund.

Now that it is authorized, it is doubly important that the Act's provisions be funded properly in FY 2011 and beyond. Mentoring programs and our national network of *Mentoring Partnerships* already rely on the tremendous contributions that AmeriCorps and VISTA volunteers make, as mentors to youth in need and staff support at those organizations. Indeed, in its FY 2011 Budget Justification², the Corporation notes mentoring several times in its FY 2009 performance outcomes, such as in an increase to 65,696 children of prisoners mentored through VISTA – well above its target of 50,000 for FY 2009. The boost in service represented by the Serve America Act would allow programs and *Partnerships* to make an even more meaningful impact in our communities and help us close the gap of 15 million young people who want and need high-quality mentoring relationships.

Background on MENTOR and Youth Mentoring. MENTOR is the nation's leading advocate and resource for mentoring, delivering the research, policy recommendations, advocacy and practical performance tools that facilitate the expansion of mentoring initiatives. We believe that, with the help and guidance of an adult mentor, each child can unlock his or her potential.

For nearly two decades, MENTOR has worked to expand the world of quality mentoring. In cooperation with a national network of *Mentoring Partnerships* and with more than 4,700 mentoring programs nationwide, MENTOR helps connect young Americans who want and need caring adults in their lives with the power of mentoring.

² http://www.nationalservice.gov/pdf/2011_budget_justification.pdf

We build the infrastructure that enables mentoring programs to flourish, and we leverage resources and provide tools that local mentoring programs need to operate high-quality mentoring. We also assist mentoring programs nationwide in building greater awareness of the need for mentors, and raising the profile of mentoring among corporate leaders, foundation executives, policymakers and researchers.

Three million young people are currently benefiting from the guidance of caring adult mentors under our system. And through the combined efforts of the mentoring field, we seek to close the mentoring gap so that the 15 million children who currently need mentors also can benefit from caring mentors.

It is on behalf of these 4,700 mentoring programs, the national network of *Mentoring Partnerships* and 15 million children who need mentors all across our country that we submit this testimony today.

Benefits of Mentoring. Youth mentoring is a simple, yet powerful concept: an adult provides guidance, support and encouragement to help a young person achieve success in life. Mentors serve as role models, advocates, friends and advisors.

Mentoring today offers many options – the traditional one-to-one format, team and group mentoring, peer mentoring and even online mentoring. And mentoring programs are run by nonprofit community-based organizations, schools, faith-based organizations, local government agencies, workplaces and more.

Numerous program evaluations have demonstrated that high-quality mentoring relationships can lead to a range of positive outcomes. A meta-analysis of 55 mentoring program evaluations (DuBois et al., 2002) found benefits of participation in the areas of emotional/psychological well-being, involvement in problem/high-risk behavior and academic outcomes. Looking at a broader range of outcomes, Eby, Allen, Evans, Ng and DuBois (2008) conducted a meta-analysis of 40 youth mentoring evaluations, and found that youth in mentoring relationships fared significantly better than non-mentored youth. Likewise, a recent large randomized evaluation of BBBSA's newer, school-based mentoring (Herrera, Grossman, Kauh, Feldman, and McMaken, 2007) revealed improvements in mentored youth's academic performance, perceived scholastic efficacy, school misconduct and attendance relative to a control group of non-mentored youth. In short, mentoring is an effective strategy that addresses both the academic and nonacademic needs of struggling young people. It can help ensure that students come to school and are ready and able to learn.

Mentoring's Impact on the Drop Out Rate. Mentoring addresses a particular challenge facing our nation today: the high rate at which young people drop out of high school. Nearly one-third of all high school students drop out before receiving their diploma, a rate which approaches 50 percent for minority students. Research on the dropout rate shows that young people can fail to graduate for a wide variety of reasons, including: lack of connection to the school environment, lack of motivation or

inspiration, chronic absenteeism, lack of parental involvement, personal reasons such as teen pregnancy and failing in school.^{3,4}

We know that young people who drop out will face a future of unemployment, government assistance and even criminal involvement. We need to help these young people before they reach the point of dropping out of high school. Fortunately, youth mentoring can play an important role in addressing the issues young people face within the learning environment. Research demonstrates that many of the impacts of mentoring can directly address the underlying causes of our nation's dropout crisis. Specific impacts of mentoring include:

- Mentored youth feel greater competence in completing their schoolwork⁵, which is linked to higher levels of classroom engagement and higher grades.⁶
- School-based mentoring enhances connectedness to schools, peers and society⁷, and mentored youth have more positive attitudes toward school and teachers⁸.
- Evaluations of mentoring programs indicated that both one-to-one mentoring and group mentoring result in better school attendance for mentored youth.⁹
- Mentored youth experience improvements in parental relationships and their own sense of self-worth.¹⁰
- Mentored youth are significantly less likely to participate in high-risk behaviors, including substance abuse, carrying a weapon, unsafe sex and violent behaviors.¹¹

Mentoring is an important tool to help address dropout risk factors and help ensure that young people are supported in their effort to graduate from high school and make a successful transition to adulthood.

High-Quality Mentoring Generates the Strongest Impact. Like any youth-development strategy, mentoring works best when measures are taken to ensure quality and effectiveness. Money, personnel and resources are required to initiate and support quality mentoring relationships. The average per-child expenditure for a mentoring match that adheres to *The Elements of Effective Mentoring Practice*TM – the mentoring industry standard – is between \$1,000 and \$1,500 per year, depending on the program model.

³ Bridgeland, John M. et al. (2006). *The Silent Epidemic: Perspectives of High School Dropouts*. Civic Enterprises in Association with Peter D. Hart Research Associates for the Bill & Melinda Gates Foundation.

⁴ Harmacek, Marilyn, ed. (2002). *Youth Out of School: Linking Absences to Delinquency*. 2nd Edition. Colorado: The Colorado Foundation for Families and Children.

⁵ Linnehan, F. (2005) "The relation of a work-based mentoring program to the academic performance and behavior of African American students," *Journal of Vocational Behavior*, 59(3).

⁶ Utman, C. H. (1997). Performance effects of motivational state: A meta-analysis. *Personality and Social Psychology Review*, 1, 170-182.

⁷ Karcher, M.J. (2005). "The effects of school-based mentoring and high school mentors' attendance on their younger mentees' self-esteem, social skills and connectedness." *Psychology in the Schools*.

⁸ Jekielek, Susan M. et al. (2002). *Mentoring: A Promising Strategy for Youth Development*. ChildTrends Research Brief, Washington, DC.

⁹ Sipe, Cynthia L. (1999). *Mentoring Adolescents: What have we learned?* Contemporary Issues in Mentoring, Grossman, Jean Baldwin (ed), Public/Private Ventures.

¹⁰ Jekielek, Susan M., et al. (2002). *Mentoring Programs and Youth Development: A Synthesis*. ChildTrends, Washington, DC.

¹¹ Beier, Rosenfeld, Spitalny, Zansky, and Bontemppo. (2000). "The potential role of an adult mentor in influencing high-risk behaviors in adolescents." *Archives of Pediatric Medicine* 15.

Successful mentoring programs must have well-trained staff familiar with the needs of the community. One-third of mentoring programs indicate that hiring and retaining quality staff can be a challenge due to low salaries. A recruitment campaign must be conducted to attract volunteers, as many programs have young people on their waiting lists for mentors.

Program staff must interview each potential volunteer, check references and perform criminal background checks. Thorough background checks alone can cost as much as \$50 - \$90 per volunteer. Once the screening process is complete, each mentor must receive first-rate training before being matched with a mentee. The work of the mentoring program does not end with the first meeting of the mentor and young person – both require ongoing support, monitoring and guidance.

All of these elements are critical because research clearly links program quality with positive outcomes. According to Dr. Jean Rhodes, professor of psychology at University of Massachusetts at Boston, careful screening, training and ongoing support are essential to the longevity of mentoring relationships and to the ultimate success of mentoring relationships.

Rhodes also found that the longer a mentoring relationship lasts, the greater the positive, long-lasting effect it has on a young person. Other researchers in the field have substantiated her findings¹². In essence, when properly prepared and supported, a mentor is more likely to connect with the young person and to stick with the relationship when times get hard.

Need for Federal Dollars. The mentoring field needs continued access to federal funds if we are to be able to serve more children, and serve them well. Once again, America has a wide mentoring gap of nearly 15 million young people. The demand for mentoring far exceeds the current capacity of local mentoring programs and the number of adults who volunteer as mentors, and thousands of children sit on waiting lists for mentors. As noted above, it takes financial resources to be able to adhere to mentoring best practices and provide quality mentoring experiences to young people.

On behalf of the thousands of mentoring programs and millions of mentored children across the country, we commend you for your past support of mentoring and national and community service funding. We strongly encourage you to continue this wise investment in our young people and in our country. Thank you for your consideration.

¹² Dubois, D.L. (2000) "Effectiveness of Mentoring Programs for Youth: A Meta-analytic Review," *American Journal of Community Psychology*, 30(2).; and Public/Private Ventures (2000). *Mentoring School-Age Children: Relationship Development in Community-Based and School-Based Programs*.

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Dear Members of the House Appropriations Committee:

I would like to take this opportunity to speak up against the idea of a fee-based Voluntary Protection Programs (VPP). As an employee at a VPP site, I believe that this will be detrimental to the integrity of the program and the culture of pro-active safety and health beyond compliance that it currently instills.

In his report to the House Budget Committee on March 4, 2010, Congressman George Miller (D-CA), chair of the House Committee on Education and Labor, supported the Department of Labor's (DOL) shift of funding and resources away from VPP in favor of enforcement. He proposed to fund VPP *"through a user fee, and plans to work on establishing authority for augmenting the OSHA budget through a fee based system"*. Funding VPP through a user-fee system for certification would take away from the independent verification of our safety and health management system because it would lead to a direct relationship between number of VPP sites and fees paid to the government. Some repeated concerns expressed by many of our 921,000 American workers now covered by VPP include:

- Industry directly funding the government to perform part of its required function under the OSH Act.
- Creating the perception that employers are "buying" the VPP flag.
- Creating a situation where employers can be perceived as purchasing "an exemption from routine OSHA inspections."
- Fees for VPP deterring small businesses from participating.
- Charging sites for participation in VPP despite of what VPP sites voluntarily give in the form of mentoring, outreach, assist visits, funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national conferences.
- Paying a fee reduces VPP to a government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride.

In a way, America's worksites would be directly funding the Occupational Safety and Health Administration (OSHA) to perform its functions as required by the OSH Act and private industry and special interests' funding the Federal Government is against the law. The Occupational Safety and Health Act of 1970 requires 13 objectives to be accomplished. Only **one** of the 13 objectives is enforcement, **two** are standard setting, and **three** are directly related to the development of cooperation between employer and employee to establish a safe workplace –

exactly what the founders of OSHA VPP established the program to accomplish. Congress and DOL taking actions to shift funding from VPP in favor of enforcement is not a return to OSHA's 'roots in enforcement,' only an Agency ignoring 12 other mandates from Congress and asking American's worksites to provide that funding through a user fee-based system to pay the agency to implement all the requirements under the OSH Act.

Unlike many fee-based certification programs, VPP is a comprehensive workplace safety and health management system that is built on cooperation among workers, employers and government. If the DOL backs away from the partnership, it diminishes the program instead of strengthening OSHA's partnership with corporate America in an effort to push beyond outdated standards.

While I continue to support firm and fair enforcement as a necessary tool to reach worksites that are not voluntarily improving their safety and health programs, I firmly believe that there is clear evidence that 40 years of enforcement has failed in producing the necessary culture shift that is required to achieve measurable and sustainable improvements in the protection of the American workforce and to keep American businesses competitive in a global marketplace.

It is clear that 40 years of enforcement have left American's small businesses - collectively the largest employers and source of future "*good jobs*" - lacking. Under any administration, OSHA's dealings with America's small businesses has either been '*hands-off*' or "*penalize to closure*," because those are the only two options in an Agency focusing solely on enforcement. In recent years, smaller worksites have increased significantly within VPP, growing from 28 percent of VPP sites in 2003 to 39 percent in 2008, thanks to innovations such as mentoring and the VPP Challenge Program. These innovations are keeping employees safer at worksites that traditionally would not see an OSHA compliance inspection or, if fined, might have to go out of business or at the very least provide lay-off notices to employees to cover the citation and associated penalties. These worksites have seen the value in a proactive safety program, such as VPP, that is saving companies and taxpayers money.

In 2007, OSHA evaluated the benefits of the VPP and reported that Federal Agency VPP participants, in OSHA, the Department of Energy (DOE), the Department of Defense (DOD), and the National Parks Service, to name a few, saved the government more than \$59 million by avoiding injuries and the private sector VPP participants saved more than \$300 million. These funds are a return on investment that are funneled into new equipment, expanding production, creating '*good jobs*,' keeping '*good jobs*,' and voluntarily mentoring other work sites in the community to learn the value of VPP and keeping American workers safe. That money should not be used to fund the Federal Government to perform its required obligations under the OSH Act.

The Federal Government already benefits from its involvement in VPP and from the private sector's participation in VPP, such as:

- The \$59 million saved by Federal Agency participants in VPP is money that demonstrates

fiscal responsibility and cost avoidance and allows for the reallocation of resources to the mission of the Agency.

- The U.S. Department of Labor's Safety, Health, and Return-to-Employment (SHARE) initiative was launched in 2004 to help the Federal Government in reducing injury and illness cases and lost production day rates, and to substantially improve timely filing of injury and illness notices. Agencies that adopted VPP achieved greater and sustainable improved performance in the SHARE initiative and want to expand the VPP throughout their operations.
- The DOD, with 31 VPP sites, has seen a substantial return on investment by adopting VPP in terms of reduced injuries and illnesses and a strong improvement in maintaining mission-readiness.
- In 2003, the DOE Appropriations language noted a dramatic improvement in the safety and health within the Complex and challenged DOE to "*maintain worker safety and health performance at least to levels seen in 2002,*" that performance was achieved by 21 VPP sites in the DOE Complex.
- The cost avoidance in workers compensation for a single contractor in the DOE Complex was a \$3 million cost reduction in three years by working toward and installing VPP. That was \$3 million in taxpayers' money redirected to the DOE mission, just by preventing worker injuries.
- OSHA also directly benefits by reducing employee injuries and illnesses at three of its Regional Field Offices that are VPP.
- Additionally, when workplaces make the significant commitment to safety required by VPP, it allows OSHA to focus its resources of enforcement where they are most needed – on those companies that "*don't get it*" – as stated by the Secretary of Labor.

Recent tragic events in the American workplace cause us great concern, such as the mining disaster in West Virginia and the refinery explosion in Washington state. These events remind us that when we continue to return to only one tool in OSHA's toolbox to achieve a safe workplace – and that tool is enforcement – that we will never achieve, as a nation, the necessary culture, mindset and attributes necessary to protect our most valued asset – the American worker. Each of these tragic examples, worksites and employers had received routine inspections and citations from OSHA and the Mine Safety & Health Administration (MSHA) compliance officers. Those visits were routine, on average five inspections in the past seven years, all with citations and large fines. These events demonstrate what 40 years of enforcement have achieved; and why would recapitulating this lesson return different results? Would more workers go home to their families at night?

Instead, what if on just one of those OSHA or MSHA inspections the compliance officer would have recommended the company enter into the VPP Challenge Program?

- *What if*, through OSHA's VPP, one of those companies had learned the value, in human preservation and financially, of preventing accidents and avoiding costs and impacts to the bottom line?
- *What if* one of those companies was the first in their industry to demonstrate that safety

and profitability are achievable together?

- *What if* others in their industry took notice and started to embrace the same ideas and sought to achieve VPP status in order to maintain a competitive edge?

Would more workers then go home to their families at night?

I ask you to speak out against the idea of a fee-based Voluntary Protection Programs and to ensure the continued success of OSHA's VPP as a cooperative program by reinstating direct and continued funding in the DOL budget. Highly successful cooperative programs like VPP should be funded and expanded if OSHA is to assist American businesses in achieving the necessary cultural change required to maintain and protect American workers, which is a proven method that supports OSHA's mission. I ask that you provide full funding in the DOL budget for VPP and include specific Appropriations language to restore and direct the Agency to fund, resource load and conduct VPP assistance, application evaluations, onsite re-approvals and new onsite evaluations to the levels equal to or greater than those achieved in 2005.

Sincerely,

David Jackson, CIH, CSP
VPPPA Chairperson, and
27 years as a safety and health professional
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U.S. House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education

Written Testimony of:

John Douglass
Brigadier General (Ret.)
United States Air Force

On behalf of:

MISSION: READINESS
1212 New York Ave, NW Suite 300
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Submitted for the Record
April 16, 2010

Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to submit this testimony. My name is John Douglass and I am a Brigadier General (US Air Force, Ret.). I am also a member of MISSION: READINESS, a national bi-partisan organization led by over 100 retired Admirals, Generals, and other senior leaders of the United States Armed Forces.

As you look toward crafting the FY 2011 appropriations measure for the Departments of Labor and Health and Human Services, I urge you to increase funding for Head Start and Early Head Start by \$989 million and increase discretionary funding for the Child Care and Development Block Grant (CCDBG) by \$1 billion. Doing so will ensure that more children have access to high-quality early care and education programs that will help them cultivate the skills they need to pursue a career in the military should they choose that path.

Our goal at MISSION: READINESS is to help resolve a national dilemma that is threatening to diminish our military strength and put our national security interests at risk. Recently we released a report, based on Department of Defense data, indicating that a shocking 75 percent of all young Americans aged 17 to 24 are unable to join the military because they failed to finish high school, have criminal records, or are physically unfit. These disqualifiers are limiting the pool of available recruits and eroding our military readiness. In order to protect our nation, the next generation of Americans must be willing and able to serve.

The United States military is the most highly skilled and professional military in the world. On a daily basis, American service members are tasked with demanding and complex missions that require remarkable intelligence and fortitude. Truly, today's men and women in uniform are among the nation's best and brightest.

However, we are failing to make sure that upcoming generations are equipped to meet military standards. For example, today, approximately one out of four young Americans lacks a high school diploma. Students who have received a general equivalency degree (GED) can sometimes receive a waiver if they score well enough on the military's entrance exam. However, even with a high school degree or GED, many potential recruits still fail the Armed Forces Qualification Test (AFQT) and cannot join. The test is used by the military to determine math and reading skills. About 30 percent of potential recruits with a high school degree take the test and fail it.

The number of American youth who are unable to qualify for military service because of their criminal history is also disturbingly high. One in 10 young adults cannot join because they have at least one prior conviction for a felony or serious misdemeanor.

Those of us who have served in leadership positions in the military know our country needs to take proactive steps to ensure our military readiness for the future. One of the most important long-term investments that we can make for an effective fighting force is in the education of the American people.

Early care and education is a tested strategy to help more Americans achieve personal and career success. It is key to providing young learners with a foundation for many options in adulthood, including a career in the military should they choose to pursue one. Decades of research prove this to be true.

A long-term University of North Carolina study on the Abecedarian early education program found that by age 21, children not in the program had dropped out of high school 48 percent more often, and that those in the program were significantly more likely to be in a high-skilled job or in higher education. In a similar study, researchers followed the progress of two groups of children over the course of 40 years—one group attended a high-quality Michigan preschool (Perry), the other did not. The at-risk children who attended the early education program were 44 percent more likely to finish high school than similar children who were left out.

The research also shows that high quality pre-kindergarten programs have positive effects on children's school readiness. In a recent study in Oklahoma, the overall test scores of kindergarteners, on a combined measure of pre-reading, writing, and numeracy, were shown to increase by 16 percent when they participated in the state pre-kindergarten program for one year.

High-quality early care and education can even prevent youth involvement in crime, another disqualifier preventing young Americans from serving. In the Perry study, the children who did not participate in the preschool program were five times more likely to be repeat, criminal offenders by age 27 than their peers.

We know, from the research, that early care and education programs must be of high quality if they are to produce the kind of longitudinal outcomes for educational attainment and crime prevention that will foster improved military readiness. For over four decades, the Head Start Program has served as the nation's premier federal early care and education program, providing high-quality, voluntary early learning to millions of children around the country. Head Start already incorporates many of the key components that are indicative of a high-quality early care and education program. These range from appropriate class-size and teacher-student ratios to an emphasis on parent involvement. To ensure continued quality enhancements, a provision to set aside a percentage of additional funding for the purpose of quality improvements, like increased teacher qualifications, was included in the 2007 reauthorization of the program.

Head Start is an important program and long-term research shows it can help improve graduation rates and decrease crime. While a recent national study of Head Start showed less than encouraging results on language and literacy skills for children by the end of first grade, Head Start's positive results for children parallel at a more modest level the very impressive results for high-quality early education programs. Recent efforts to improve Head Start as part of the 2007 reauthorization came after that particular study was initiated, so additional improvements to program quality are already underway. But the mixed results further reinforce the need to make sure the improvements in quality continue to take place so Head Start can realize its full potential to turn around the lives of at-risk children. We need to make sure that Head Start reaches more at-risk kids and that it provides continually improving services to those kids.

The contrasts could not be clearer. Children who attend quality early education programs enter kindergarten more prepared, are more likely to pursue higher education, and are more likely to be employed. Those who lack early learning experiences are less likely to graduate and more likely to become criminals.

Unfortunately, there is still a considerable unmet need for Head Start, Early Head Start, and the Child Care and Development Block Grant (CCDBG). Currently, Head Start serves less than half of those eligible and Early Head Start serves less than 5 percent of eligible infants and toddlers nationally. For every 7 children eligible for subsidies under CCDBG, only one receives quality childcare through the program.

Thank you again for the opportunity to provide testimony on this important matter. To be sure, our military stands ready to protect against those who would threaten our security. But in order to sustain our military strength for the future, we must increase investments in quality early care and education to ensure that upcoming generations of Americans will be fit to serve in a 21st century military.

STATEMENT BY THE
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FY 2011 APPROPRIATIONS FOR LABOR-HHS-EDUCATION
NATIONAL INSTITUTES OF HEALTH

I am Flora Ingenhouz, a psychotherapist in private practice in Silver Spring, Maryland. I have always been in excellent health and live an active, healthy lifestyle. Doctors always commented on my low blood pressure and my excellent cholesterol numbers. But, I suffered a stroke. It was a shock to me and my family, friends and clients.

One morning four years ago, when doing a load of laundry, I had no idea how to set the dials, despite the fact that I had used these dials weekly for the last ten years. I stood there for what seemed an eternity before I figured out how to set them.

Next I went to do yoga. In one of the poses, I noticed my right arm was hanging limp. When my husband asked me a question, my answer was just the opposite of what I wanted to say. I caught my error and tried again, but it soon became clear that something was wrong. My symptoms kept getting worse.

When we walked into the ER, my right leg was weak, and I could not sign my name at the desk. Twelve hours later, I could not move my right side, and my speech was reduced to yes and no. Not a good thing for a psychotherapist, where language is a primary tool!

In the ER, a CT scan showed a hemorrhagic or bleeding stroke where an artery burst, destroying millions of brain cells within minutes, affecting my speech and my ability to perform activities like dressing in the correct order. Also, my right arm and leg were extremely weak. However, I could understand everything, and I was never completely paralyzed. But, I was scared.

I was in intensive care for four days of observation and lots of testing, but the tests provided no answers. Two days after my stroke, while still in intensive care, I started occupational, physical and speech therapy. It was extremely challenging to feed myself with my right hand, requiring all my concentration. After a meal or brushing my teeth, I was exhausted. Speaking was the hardest of all. My brain seemed devoid of words.

After being stabilized, I was transferred to the National Rehabilitation Hospital. For a week, I endured speech, physical, occupational and recreational therapies.

Speech therapy was the hardest, but also the most important given my profession. Several times, the speech therapist challenged me to the brink of tears.

After a week at the Rehabilitation Hospital, I went home and to outpatient therapies. Speech therapy lasted the longest. After being discharged from speech therapy, I still had deficits in my organizational skills and abstract thinking.

As I struggled with starting to see my clients again, I slid into a deep depression. I was not confident that I could continue to practice. For months, I saw no point in living. Recovery from my post-stroke depression was harder than the recovery of my arms and legs and even speech!

Being a psycho-therapist, I know how to treat depression, so I went to a psychiatrist who prescribed anti-depressant medication and, I also found a psychotherapist.

After months on anti-depressants and excellent psychotherapy, my depression began to lift. I continue on the drugs and to see my psychotherapist. Emotionally, the aftermath of my stroke cut deep.

I am fortunate that four years post-stroke, I am back to full-time practice. I lead support groups for stroke survivors and caregivers through the Montgomery County Stroke Association and serve on its Board. I also lecture on stroke, stroke prevention and stroke recovery. I founded "Hope after Stroke"--individual and family counseling for stroke survivors and caregivers. In addition, I have participated in NIH studies about stroke recovery.

Once again, I am in excellent health and have resumed my active life style. I thank my brain for having the capacity to work around the dead cells. But most of all, I thank my therapists for my recovery. Their ability to zero in so effectively would not have been possible without NIH research.

Because stroke is a leading cause of death and disability and major cost to society, I urge you to provide stroke research with a significant funding increase. I am concerned that NIH continues to invest only 1 percent of its budget in stroke research.

Thank you.

WRITTEN TESTIMONY OF JOHN E. MAUPIN, D.D.S., MBA
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PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION AND RELATED AGENCIES

SUMMARY OF FISCAL YEAR 2011 RECOMMENDATIONS:

- 1) \$300 MILLION FOR THE TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS, INCLUDING:
 - \$33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.
 - \$35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.
- 2) \$500 MILLION FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES.
- 3) SUPPORT FOR THE NATIONAL CENTER FOR RESEARCH RESOURCES EXTRAMURAL FACILITIES CONSTRUCTION PROGRAM.
 - a. PROPORTIONAL INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.
 - b. \$ 50 MILLION FOR EXTRAMURAL FACILITIES CONSTRUCTION.
- 4) \$75 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH.
- 5) \$75 MILLION FOR THE DEPARTMENT OF EDUCATION'S STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS PROGRAM.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. John E. Maupin, President of Morehouse School of Medicine (MSM) in Atlanta, Georgia. I have previously served as President of Meharry Medical College, executive vice-president at Morehouse School of Medicine, as director of a community health center in Atlanta, and deputy director of health in Baltimore, Maryland. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

I want to say that minority health professional institutions and the Title VII Health Professions Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our nation's most medically underserved communities. Furthermore, our nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15% of the U.S. population, only 2-3% of the nation's health professions workforce is black. Morehouse is a private school with a very public mission of educating students from traditionally underserved communities so that they will care for the underserved. Mr. Chairman, I would like to share with you how your committee can help us continue our efforts to help provide quality health professionals and close our nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the federal government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. **Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.**

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Given the historic mission, of institutions like MSM, to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The slow reinvestment in the Title VII Health Professions Training programs amounts to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my dental degree from Meharry Medical College, a historically black medical and dental school in Nashville, Tennessee. I have seen first hand what Title VII funds have done to minority serving institutions like Morehouse and Meharry. I compare my days as a student to my days as president, without that Title VII, our institutions would not be here today. However, Mr. Chairman, since those funds have been slowly replenished, we are standing at a cross roads. This committee has the power to decide if our institutions will go forward and thrive, or if we will continue to try to just survive. We want to work with you to eliminate health disparities and produce world class professionals, but we need your assistance.

Minority Centers of Excellence: COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of “Hispanic”, “Native American” and “Other” Historically black COEs. *For FY11, I recommend a funding level of \$33.6 million for COEs.*

Health Careers Opportunity Program (HCOP): HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. *For FY09, I recommend a funding level of \$35.6 million for HCOPs.*

NATIONAL INSTITUTES OF HEALTH (NIH): EXTRAMURAL FACILITIES CONSTRUCTION

Mr. Chairman, if we are to take full advantage of the recent funding increases for biomedical research that Congress has provided to NIH over the past decade, it is critical that our nation’s research infrastructure remain strong. The current authorization level for the Extramural Facility Construction program at the National Center for Research Resources is \$250 million. The law also includes a 25% set-aside for “Institutions of Emerging Excellence” (many of which are minority institutions) for funding up to \$50 million. Finally, the law allows the NCRR Director to waive the matching requirement for institutions participating in the program. We strongly support all of these provisions of the authorizing legislation because they are necessary for our minority health professions training schools.

There was two year funding in the stimulus bill for extramural facilities, but we need a sustained effort to help with our research and infrastructure enterprises. *I ask that the FY 2011 L-HHS bill include at least \$50 million for this program.*

RESEARCH CENTERS IN MINORITY INSTITUTIONS: The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. *Therefore, the funding for this important program grow at the same rate as NIH overall in FY11.*

STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS - DEPARTMENT OF EDUCATION: The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In FY11, an appropriation of \$75 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

National Institute on Minority Health and Health Disparities: The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Minority Centers of Excellence program. *For FY11, I recommend a funding level of \$500 million for the NCMHD.*

Department of Health and Human Services' Office of Minority Health

Specific programs at OMH include: 1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; 2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; 3) Supporting conferences for high school and undergraduate students to interest them in health careers, and 4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities, and with the proper funding this role can be enhanced. *For FY11, I recommend a funding level of \$75 million for the OMH.*

Mr. Chairman, please allow me to express my appreciation to you and the members of this

subcommittee. With your continued help and support, Morehouse School of Medicine along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. MSM and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have since our founding day.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.



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**STATEMENT OF
ROBERT TRACHTENBERG
PRESIDENT**

THE NATIONAL AHEC ORGANIZATION

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ON THE

APPROPRIATIONS FOR

AREA HEALTH EDUCATION CENTERS

APRIL 16, 2010

SUMMARY OF RECOMMENDATIONS:

- 1. THE AREA HEALTH EDUCATION CENTER PROGRAM IS EFFECTIVE AND PROVIDES VITAL SERVICES AND NATIONAL INFRASTRUCTURE.**
- 2. AREA HEALTH EDUCATION CENTERS ARE THE WORKFORCE DEVELOPMENT, TRAINING AND EDUCATION MACHINE FOR THE NATION'S HEALTH CARE SAFETY-NET PROGRAMS.**
- 3. FUND THE AREA HEALTH EDUCATION CENTER PROGRAM AT THE LEVEL OF \$125 MILLION.**



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The National AHEC Organization (NAO) is the professional organization representing Area Health Education Centers (AHECs). Our message is simple:

- **The Area Health Education Center program is effective and provides vital services and national infrastructure.**
- **Area Health Education Centers are the workforce development, training and education machine for the nation's health care safety-net programs.**

AHEC is one of the Title VII Health Professions Training programs, originally authorized at the same time as the National Health Service Corps (NHSC) to create a complete mechanism to provide primary care providers for Community Health Centers (CHCs) and other direct providers of health care services for underserved areas and populations. The plan envisioned by creators of the legislation was that the CHCs would provide direct service. The NHSC would be the mechanism to fund the education of providers and supply providers for underserved areas through scholarship and loan repayment commitments. The AHEC program would be the mechanism to recruit providers into primary health careers, diversify the workforce, and develop a passion for service to the underserved in these future providers, i.e. **Area Health Education Centers are the workforce development, training and education machine for the nation's health care safety-net programs.** The AHEC program is focused on improving the quality, geographic distribution and diversity of the primary care healthcare workforce and eliminating the disparities in our nation's healthcare system.

AHECs develop and support the community based training of health professions students, particularly in rural and underserved areas. They recruit a diverse and broad range of students into health careers, and provide continuing education, library and other learning resources that improve the quality of community-based healthcare for underserved populations and areas.

The Area Health Education Center program is effective and provides vital services and national infrastructure. Nationwide, in 2006, AHECs introduced over 308,000 students to health career opportunities, and over 41,000 mostly minority and disadvantaged high school students received more than 20 hours each of health career programs and academic enhancement. AHECs support health professional training in over 19,000 community based practice settings, and over 111,000 health professional students received training at these sites. Further, over 368,000 health professionals received continuing education through AHECs. AHECs perform these education and training services through collaborative partnerships with Community Health Centers (CHCs) and the National Health Service Corps (NHSC), in addition to Rural Health Clinics (RHCs), Critical Access Hospitals, (CAHs), Tribal clinics and Public Health Departments.

While our partner programs, the National Health Service Corps and the Community Health Centers program have received much recognition of late and are identified as Presidential Initiatives, the AHEC program has



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been overlooked. AHEC is designed to meet the needs of the communities it serves, and to bridge the resources of universities, state and federal programs, bringing those resources to the community. As a program with a national network, AHEC has a significant infrastructure. This infrastructure can provide the mechanism for information dissemination for Clinical and Translational Services to reduce the time it takes for bench science findings to become part of medical practice. AHECs can deliver minority health programs and already focus on recruiting minorities into health careers.

In the past decade many new programs have been developed by federal initiatives which compete with the mission of AHEC and utilize federal resources to duplicate the AHEC infrastructure. Public resources would be better spent by utilizing the national network that AHEC represents, rather than reproducing the infrastructure through the creation of other programs.

AHEC was recently reauthorized in the Patient Protection and Affordable Care Act of 2010. We were pleased to that this program was reauthorized for the first time since 1998, and reauthorized at \$125 million.

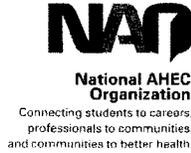
Community Health Centers and the National Health Service Corps

CHCs are dedicated to providing preventive and ambulatory healthcare to uninsured and underinsured populations. A March 2006 study published in the *Journal of the American Medical Association (JAMA)* found that CHCs report high percentages of provider vacancies, including an insufficient supply of dentists, pharmacists, pediatricians, family physicians and registered nurses. These shortages are particularly pronounced in CHCs that serve rural areas. The study serves as an important reminder that the success of CHCs is highly dependent upon a well-trained clinical staff to provide care. Because Title VII programs, including AHECs, have a successful record of training providers to work in underserved areas, the study recommends increased support for the Title VII Health Professions Training programs as the primary means of alleviating the health professions shortage in rural CHCs. In 2006, forty-six percent of AHEC training sites were CHCs, and an additional 25% of placements were in Rural Health Clinics.

The scope of collaborative activities between AHECs and CHCs is substantial and the populations served through these activities are culturally and geographically diverse. The interrelationships between AHECs and CHCs are numerous, and the added-value to the community from the unique contributions of each is undeniable in terms of access to quality health care.

AHECs collaborate with CHCs by:

- ❖ Assisting CHCs with the development of community boards of directors and often serving as board members;
- ❖ Recruiting health professionals/staff;
- ❖ Facilitating clinical training opportunities for health professions students/trainees within CHC clinic sites;



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- ❖ Conducting continuing education programs and other library and learning resources for health and human services professionals employed at CHC clinic sites.

AHECs also undertake a variety of programs related to the placement and support of National Health Service Corps scholars and loan repayment recipients. NHSC scholars and loan repayment recipients commit to practicing in an underserved area, and are focused on improving health by providing comprehensive team-based healthcare that bridges geographic, financial and cultural barriers. As contractors of the NHSC Student/Resident Experiences and Rotations in Community Health (SEARCH) program, AHECs help to expand the NHSC by placing students and residents in rotations in rural areas. These students and residents are then more likely to return to rural and underserved areas as a NHSC scholar or loan repayment recipient since health professionals who spend part of their training providing care for rural and underserved populations are 3 to 10 times more likely to practice in rural and underserved areas after graduation or program completion.

AHECs frequently place health professions students in sites that are approved for NHSC personnel. NHSC scholars and loan repayers serve as preceptors or these students. These sites give the students a view of working in communities with great need, seeing the potential for a fulfilling career, thus strengthening the connection between these students and service to the underserved through the NHSC.

Justification for Recommendations

By improving the quality, geographic diversity, and diversity of the healthcare workforce, the United States can eliminate healthcare disparities. An October 2006 study by the Health Resources and Services Administration (HRSA) entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" shows the importance of the programs like AHEC. This study found that minority health professionals disproportionately serve minority and other medically underserved populations, minority populations tend to receive better care from practitioners of their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their own language.

In order to continue the progress that the Title VII Health Professions Training programs, especially AHECs, have already made towards their goal, an additional federal investment is required. **NAO recommends that the AHEC program is funded at \$125 million, consistent with its recent reauthorization amount.**



NAEVR

National Alliance For
Eye And Vision Research

Serving as Friends of the National Eye Institute

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**WRITTEN TESTIMONY IN SUPPORT OF INCREASED
FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH (NIH)
AND THE NATIONAL EYE INSTITUTE (NEI)
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED
AGENCIES SUBCOMMITTEE OF THE U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON APPROPRIATIONS
April 8, 2010**

EXECUTIVE SUMMARY

NAEVR requests Fiscal Year (FY) 2011 NIH funding at \$35 billion, which reflects a \$3 billion increase over President Obama's proposed funding level of \$32 billion. Funding at \$35 billion, which reflects NIH's net funding levels in both FY2009 and FY2010, ensures it can maintain the number of multi-year investigator-initiated research grants, the cornerstone of our nation's biomedical research enterprise. The vision community commends Congress for \$10.4 billion in NIH funding in the American Recovery and Reinvestment Act (ARRA), as well as FY2009 and FY2010 funding increases that enabled NIH to keep pace with biomedical inflation after six previous years of flat funding that resulted in a 14 percent loss of purchasing power. FY2011 NIH funding at \$35 billion enables it to meet the expanded capacity for research— as demonstrated by the significant number of high-quality grant applications submitted in response to ARRA opportunities—and to adequately address unmet need, especially for programs of special promise that could reap substantial downstream benefits, as identified by NIH Director Francis Collins, M.D., Ph.D. in his top five priorities. As President Obama has stated repeatedly, including at a visit to the NIH in September 2009, biomedical research has the potential to reduce healthcare costs, increase productivity, and ensure the global competitiveness of the United States.

NAEVR requests that Congress improve upon the President's proposed 2.5 percent NEI increase—the second smallest increase of all Institutes and Centers—especially if it does not increase overall NIH funding above the President's request.

In 2009, Congress spoke volumes in passing S. Res 209 and H. Res, 366, which acknowledged NEI's 40th anniversary and designated 2010-2020 as *The Decade of Vision*, in which the majority of 78 million Baby Boomers will turn 65 years of age and face greatest risk of aging eye disease. This is not the time for a less-than-inflationary increase that nets a loss in the NEI's purchasing power, which eroded by 18 percent in the FY2003-FY2008 timeframe. NEI-funded research is resulting in treatments and therapies that save vision and restore sight, which can reduce healthcare costs, maintain productivity, ensure independence, and enhance quality of life.

FY2011 NIH FUNDING AT \$35 BILLION ENABLES THE NEI TO BUILD UPON THE IMPRESSIVE RECORD OF BASIC AND CLINICAL COLLABORATIVE RESEARCH THAT MEETS NIH'S TOP FIVE PRIORITIES AND WAS FUNDED THROUGH FY2009-2010 ARRA AND INCREASED "REGULAR" APPROPRIATIONS

NEI's research addresses the preemption, prediction, and prevention of eye disease through basic, translational, epidemiological, and comparative effectiveness research which also address the top five NIH priorities, as identified by Dr. Collins: genomics, translational research; comparative effectiveness; global health, and empowering the biomedical enterprise. NEI continues to be a leader within the NIH in elucidating the genetic basis of ocular disease—NEI Director Paul Sieving, M.D., Ph.D., has reported that one-quarter of all genes identified to date through collaborative efforts with the National Human Genome Research Institute (NHGRI) are associated with eye disease/visual impairment.

NEI received \$175 million of the \$10.4 billion in NIH ARRA funding. As a result, NEI's total funding levels in the FY2009-2010 timeframe were \$776 million and \$794.5 million, respectively. In FY2009, NEI made 333 ARRA-related awards, the majority of which reflect investigator-initiated research that funds new science or accelerates ongoing research, including ten Challenge Grants. Several examples of research, and the reasons why it is important, include:

- **Biomarker for Neovascular Age-related Macular Degeneration (AMD):**
Researchers will use a recently discovered biomarker for choroidal neovascularization (CNV)—the growth of abnormal blood vessels into the retina and responsible for 90 percent of vision loss associated with AMD—to develop an early detection method to minimize vision loss. *Why important? AMD is the leading cause of vision loss in the U.S., especially in the elderly.*
- **Cellular Approach to Treating Diabetic Retinopathy (DR):**
Researchers propose to develop a clinical treatment for diabetic retinopathy—in which diabetes damages small blood vessels in the retina, causing them to leak—that uses stem cells from the patient's own blood that have been activated outside of the body and then returned to repair damaged vessels in the eye. *Why important? DR is the leading cause of vision loss in younger Americans, and its incidence is disproportionately higher in African Americans, Latinos, and Native Americans.*
- **Small Heat Shock Proteins as Therapeutic Agents in the Eye:**
Researchers propose to develop new drugs to prevent or reverse blinding eye diseases, such as cataract (clouding of the lens), that are associated with the aggregation of proteins. Research will focus on the use of small "heat shock" proteins that facilitate the slow release and prolonged delivery of targeted macromolecules to degenerating cells of the eye. *Why important? Delivering effective, long-lasting therapies through a minimally invasive route into the eye is a major challenge.*

- **Identification of Genes and Proteins that Control Myopia Development:**
Researchers propose to identify targets that will facilitate development of interventions to slow or prevent myopia (nearsightedness) development in children. Identifying an appropriate myopia prevention target can reduce the risk of blindness and reduce annual life-long eye care costs. *Why important? More than 25 percent of the U.S. population has myopia, costing \$14 billion annually, from adolescence to adulthood.*
- **Comparison of Interventions for Retinopathy of Prematurity (ROP):**
In animal studies, researchers will simulate Retinopathy of Prematurity—a blinding eye disease that affects premature infants—and then study novel treatments that involve modulating the metabolism of the retina’s rod photoreceptors. *Why important? ROP affects 15,000 children a year, about 400-600 of whom progress to blindness, at an estimated lifetime cost for support and unpaid taxes of \$1 million each.*
- **The NEI Glaucoma Human genetics collaBORation, NEIGHBOR:**
This research network, in which seven U.S. teams will lead genetic studies of the disease, may lead to more effective diagnosis and treatment. Researchers were primarily funded through ARRA supplements. *Why important? Glaucoma, a complex neurodegenerative disease that is the second leading cause of preventable blindness in the U.S., often has no symptoms until vision is lost.*
- **Comparative Effectiveness of Interventions for Primary Open Angle Glaucoma (POAG):**
Researchers will evaluate existing data on the effectiveness of various treatment options for primary open angle glaucoma—many emerging from past NEI research. *Why important? POAG is the most common form of the disease, which disproportionately affects African Americans and Latinos.*

In addition to ARRA funding, the “regular” appropriations increases in FY2009-2010 enabled the NEI to continue to fund key research networks, such as the following:

- **The African Descent and Glaucoma Evaluation Study (ADAGES)**, which is designed to identify factors accounting for differences in glaucoma onset and rate of progression between individuals of African and European descent.
- **The Diabetic Research Clinical Research Network’s (DRCR)** initiation of new trials comparing the safety and efficacy of drug therapies as an alternative to laser treatment for diabetic macular edema and proliferative diabetic retinopathy.
- **The Neuro-Ophthalmology Research Disease Investigator Consortium (NORDIC)**, which will lead multi-site observational and treatment trials, involving nearly 200 community and academic practitioners, to address the risks, diagnosis, and treatment of visual dysfunction due to increased intracranial pressure and thyroid eye disease.

The unprecedented level of FY2009-2010 vision research funding is moving our nation that much closer to the prevention of blindness and restoration of vision. With an overall NIH funding level of \$35 billion, which translates to an NEI funding level of \$794.5 million, the vision community can accelerate these efforts, thereby reducing healthcare costs, maintaining productivity, ensuring independence, and enhancing quality of life.

**IF CONGRESS DOES NOT INCREASE FY2011 NIH FUNDING ABOVE
THE PRESIDENT'S REQUEST, IT IS EVEN MORE VITAL TO IMPROVE UPON THE
PROPOSED 2.5 PERCENT INCREASE FOR NEI**

The NIH budget proposed by the Administration and developed by Congress during the very first year of the Congressionally-designated *Decade of Vision* should not contain a less-than-inflationary increase for the NEI due to the enormous challenges it faces in terms of the aging population, the disproportionate incidence of eye disease in fast-growing minority populations, and the visual impact of chronic disease (e.g., diabetes). If Congress is unable to fund NIH at \$35 billion in FY2011 (NEI level of \$794.5 million) and adopts the President's proposal, the 2.5 percent increase in funding must be increased to at least an inflationary level of 3.2 percent to prevent any further erosion in NEI's purchasing power. NEI funding is an especially vital investment in the overall health, as well as the vision health, of our nation. It can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

**VISION LOSS IS A MAJOR PUBLIC HEALTH PROBLEM: INCREASING
HEALTHCARE COSTS, REDUCING PRODUCTIVITY, DIMINISHING LIFE QUALITY**

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the US is \$68 billion, this number does not fully quantify the impact of direct healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. The continuum of vision loss presents a major public health problem and financial challenge to the public and private sectors.

ABOUT NAEVR

The National Alliance for Eye and Vision Research (NAEVR) is a 501(c)4 non-profit advocacy coalition comprised of 55 professional, consumer, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyersearch.org.

Testimony for Submission

Julie M. Scofield
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To the House Committee on Appropriations
Subcommittee on Labor, HHS, Education and Related Agencies
For FY2011

The National Alliance of State and Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV/AIDS and viral hepatitis healthcare, prevention, education, and supportive service programs funded by state and federal governments.

On behalf of NASTAD, we urge your support for increased funding for federal HIV/AIDS and viral hepatitis programs in the FY2011 Labor-Health-Education Appropriations bill. We ask the Subcommittee on Labor-HHS-Education to demonstrate its commitment to addressing the domestic HIV epidemic and ramp up support for a much larger blood-borne epidemic, that of chronic viral hepatitis. We thank you once again for the increases provided to HIV/AIDS and hepatitis programs in FY2010 and ask for consideration of the following critical funding needs for HIV/AIDS, viral hepatitis and STD programs in FY2011.

HIV/AIDS Care and Treatment Programs

The Health Resources and Services Administration (HRSA) administers the \$2.2 billion Ryan White Program that providing health and support services to over 500,000 HIV-positive individuals. NASTAD requests a minimum increase of **\$426 million** in FY2011 for state Ryan White Part B grants, including an increase of **\$56 million** for the Part B Base and **\$370 million** for AIDS Drug Assistance Programs (ADAPs). With these funds states and territories provide care, treatment and support services to persons living with HIV/AIDS. People living with HIV need access to trained HIV clinicians, life-saving and life-extending therapies, and a full range of support services to live as healthy a life as possible and to ensure adherence to complicated treatment regimens. All states are reporting to NASTAD that they are seeing a significant increase in the number of individuals seeking Part B Base and ADAP services. In 2008, it is estimated that ADAPs nationwide served nearly 165,000 HIV-infected individuals, nearly one-quarter of people with HIV/AIDS estimated to be receiving care. This is due to a number of factors including, increased testing efforts and unemployment.

State ADAPs provide medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid. With the rise in unemployment and individuals losing their insurance, ADAPs are increasingly in crisis. As of April 2010, ten states report that 859 individuals are on a waiting list to receive their life-sustaining medications through ADAP:

Idaho: 25 individuals

Iowa: 62 individuals

| | |
|--|-------------------------------------|
| Kentucky: 191 individuals | South Dakota: 32 individuals |
| Montana: 17 individuals | Tennessee: 55 individuals |
| North Carolina: 356 individuals | Utah: 74 individuals |
| South Carolina: 33 individuals | Wyoming: 14 individuals |

Sixteen states have additional cost containment measures in place or are anticipating implementing measures.

ADAPs with Other Cost-containment Strategies (instituted since April 1, 2009)

| | |
|---|--|
| Arizona: reduced formulary | Kentucky: reduced formulary |
| Arkansas: reduced formulary, lowered financial eligibility to 200% of FPL | Missouri: reduced formulary |
| Colorado: reduced formulary | North Carolina: reduced formulary |
| Hawaii: individuals with CD4>350 not currently on ARV therapy are not being enrolled | North Dakota: cap on Fuzeon |
| Iowa: reduced formulary | Utah: reduced formulary, lowered financial eligibility to 250% of FPL |
| | Washington: client cost sharing, reduced formulary (for uninsured clients only) |

ADAPs Considering New/Additional Cost-containment Measures (before March 31, 2011)

| | |
|---|---|
| Arizona: waiting list | North Dakota: waiting list, reduced formulary, capped enrollment, annual expenditure cap |
| Hawaii: waiting list | Oregon: waiting list, reduced formulary |
| Illinois: waiting list, reduced formulary, lowered financial eligibility, capped enrollment, monthly expenditure cap | South Dakota: reduced formulary |
| Kentucky: reduced formulary | Wyoming: lowered financial eligibility, annual expenditure cap |
| Louisiana: capped enrollment | |
| North Carolina: lowered financial eligibility | |

In FY2009, 48 percent of ADAPs experienced cuts in state contributions to their programs and at least 35 percent of programs are anticipating cuts to their ADAPs in FY2010. Program restrictions can lead to dangerous treatment interruptions, which encourage drug resistance and discourage patient retention in care, both of which have profound effects on public health. As discretionary programs, ADAPs are dependent on annual federal and state appropriations to serve all those in need of treatment.

Ryan White Part B Base programs include ambulatory medical services, case management, laboratory services, and primary care networks that improve the overall HIV care systems in states. Primary care and the provision of drug treatments are inextricably linked. People living with HIV need access to trained HIV clinicians and a full range of support services to live as healthy a life as possible to ensure adherence to complicated treatment regimens. Unfortunately, limited funding has resulted in waits of up to six months for a primary care visit.

HIV/AIDS Prevention and Surveillance Programs

NASTAD requests an increase of **\$181 million** for state and local health department cooperative agreements in order to provide comprehensive prevention programs. To be successful, health departments must expand outreach, HIV testing, and linkage into care targeting high-risk

populations including gay men of all races, black women, persons who inject drugs, and youth. Additional resources must be directed to build capacity and provide technical assistance to enable community-based organizations and health care providers to implement evidence-based behavior change interventions and HIV testing recommendations. In order to maximize prevention efforts, partners of persons being tested need to be identified, notified, and counseled. In addition, health departments need resources to educate the mass public by reinforcing accurate, evidence-based information and beginning to reduce the stigma associated with the disease.

An estimated 56,300 new infections occur every year while state and local HIV prevention cooperative agreements have been cut by \$23 million over the last decade. NASTAD surveyed states and found that in FY2009, state HIV/AIDS programs were cut by \$170 million. Seventy-four percent of states responding to NASTAD's survey reported cuts to HIV prevention programs. States also reported that almost 200 HIV/AIDS staff positions have been cut or gone unfilled. These cuts make the federal resources for prevention all the more critical to mounting an effective response to the epidemic.

The nation's prevention efforts must match our commitment to the care and treatment of infected individuals. State and local public health departments know what to do to prevent new infections, they just need the resources. First and foremost we must address the devastating impact on racial and ethnic minority communities. To be successful, we must expand outreach and HIV testing efforts targeting high-risk populations including gay and bisexual men of all races, racial and ethnic minority communities, substance users, women and youth. But, testing alone can never end the epidemic. All tools in the prevention arsenal must be supported. Additional resources must be directed to build capacity and provide technical assistance to enable community-based organizations and health care providers to implement evidence-based behavior change interventions and HIV testing recommendations. In order to maximize prevention efforts, partners of persons being tested need to be identified, notified, and counseled. With twenty-one percent of HIV-infected persons unaware that they have HIV, increased funding for testing and partner services will avert millions in unnecessary health care costs. In addition, health departments need resources to educate the mass public by reinforcing accurate, evidence-based information and beginning to reduce the stigma associated with the disease.

NASTAD also supports the President's request of **\$26.9 million** for a new initiative targeting gay men and other men who have sex with men (MSM). We believe this funding should come out of HIV funding and not STD and viral hepatitis increases as proposed.

NASTAD requests that **\$48 million** be allocated to health departments to maintain the Expanded Testing Initiative (ETI). In FY2009, CDC awarded \$40.2 million to 20 states and 5 cities to support routine testing in clinical settings targeting highly impacted populations, particularly African Americans. In FY2010, the ETI will be expanded to 24 states and 6 cities funded at \$47.5 million targeting African Americans, Latinos, gay and bisexual men of all races, and persons who inject drugs. NASTAD supports maintaining \$48 million for health departments of the \$65 million for the entire initiative so that more individuals can learn of their HIV status and be linked into care. NASTAD also support the President's request of **\$10 million** for Program

Collaboration and Service Integration (PCSI) to all health departments to integrate prevention services for HIV, STD, viral hepatitis, and TB at the client level.

Viral Hepatitis Prevention Programs

NASTAD requests an increase of **\$30.7 million** for a total of **\$50 million** in FY2011 for the CDC's Division of Viral Hepatitis (DVH) to enable state and local health departments to provide basic core public health services for viral hepatitis. Funds are needed for hepatitis B and C counseling, testing, and medical referral. States receive on average \$90,000 for adult hepatitis prevention. DVH provides \$5 million to fund the position of an Adult Viral Hepatitis Prevention Coordinator in 49 states, five cities, and the District of Columbia. This is only enough for the position and not for the provision of prevention services. Therefore, NASTAD requests a doubling of funding to the state adult viral hepatitis prevention coordinators from **\$5 to \$10 million**.

Due to lack of funding, CDC must treat hepatitis outbreaks as sentinel events rather than systematically addressing hepatitis B and C epidemics with over 6 million Americans infected. Addressing one outbreak at a time is not cost-effective nor is it preventive. The first step to controlling infectious diseases such as hepatitis B and C is establishing a surveillance system to monitor disease incidence, prevalence, and trends. While there is no vaccine for hepatitis C, investing in hepatitis A and B vaccines is essential to providing prevention for high-risk adults and the elimination of both diseases. Hepatitis disproportionately impacts minorities and must be addressed in the context of health disparities. Approximately half of persons with chronic HBV are Asian Americans. Furthermore, HBV is most prevalent among immigrants from HBV-endemic countries (Asia and sub-Saharan Africa) who were infected at birth or childhood. Of the 24,000 HBV-infected women who give birth every year, half are Asian Americans. HCV infection is 2 to 3 times as prevalent in African Americans as it is in whites.

The recently released IOM report, *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C* found that the public health response needs to be significantly ramped up. IOM's report attributes low public and provider awareness to the lack of public resources. The report makes 17 out of 22 recommendations specific to state health departments. In order to implement these recommendations to improve the federal response, resources must be increased to health departments who provide the frontline response to these epidemics. For example, hepatitis C is the most common blood-borne, chronic viral disease in the United States with up to 4 million Americans suffering from chronic HCV infection—nearly four times the amount of those with HIV. Although transmission of hepatitis C has significantly decreased in the U.S. over the past twenty years, the incidence of liver disease and liver cancer is rising, as persons infected with hepatitis C decades ago begin to develop complications of their infection. Without increased resources for counseling, testing and medical referral services, the CDC predicts that deaths due to HCV will double by 2020.

STD Prevention Programs

NASTAD supports an increase of **\$213.5 million** for a total of **\$367.4 million** in FY2011 for STD prevention, treatment and surveillance activities undertaken by state and local health departments. CDC's Division of STD Prevention has prioritized four disease prevention goals—Prevention of STD-related infertility, STD-related adverse pregnancy outcomes, STD-related

cancers and STD-related HIV transmission. STD prevention programs at CDC have been cut by \$6 million since FY2004 while the number of persons infected continues to climb. CDC estimates that 19 million new infections occur each year, almost half of them among young people ages 15 to 24. In one year, the U.S. spends over \$8 billion to treat the symptoms and consequences of STDs. Untreated STDs contribute to infant mortality, infertility, and cervical cancer. Additional federal resources are needed to reverse these alarming trends and reduce the nation's health spending.

Minority AIDS Initiative

NASTAD also supports total funding of **\$610 million** for the Minority AIDS Initiative (MAI) in FY2011. The MAI provides targeted resources to address the HIV/AIDS epidemic in hard-hit communities of color. MAI resources supplement the funding to states to address the epidemic in these communities. The data from CDC on the disproportionate impact on African American continues to be staggering. Support for the MAI along with the traditional funding streams that serve these populations is essential.

Comprehensive Sex Education

NASTAD supports the teen pregnancy prevention initiative and asks that it be expanded to include prevention of HIV and STDs and funded at the President's request of **\$134 million**. Programs targeted to youth in and out of school require an inter-departmental approach through the collaboration of HHS agencies, including the Agency for Children and Families, CDC's Division of Adolescent and School Health, and the Office of Population Affairs. We also support an increase of **\$20 million**, for a total of **\$60.2 million**, for the Division of Adolescent and School Health's HIV Prevention Education Program to increase access to evidence-based and comprehensive approach to sex education. Programs targeted to youth in and out of school require an inter-departmental approach through the collaboration of HHS agencies, including the Office of Adolescent Health, the Office of Population Affairs, the Agency of Children and Families, and CDC's Division of Adolescent and School Health.

As you craft the FY2011 Labor, HHS and Education Appropriations bill, we ask that you consider all of these critical funding needs. National Alliance of State and Territorial AIDS Directors thanks the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV, viral hepatitis and STD epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our nation's fight against these infectious and often chronic diseases.

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**Testimony of the National Association for College Admission Counseling (NACAC)
Fiscal Year 2011 Appropriations**
Submitted April 16, 2010
U.S. House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

About NACAC

The National Association for College Admission Counseling (NACAC) and its state and regional affiliates represent more than 20,000 college counseling and admission professionals nationwide. The association represents more than 1,600 high schools and 1,100 not-for-profit colleges and universities. Since its founding in 1937, NACAC's enduring goal has been to provide students greater access to higher education.

President Obama's Goal

At the start of his presidency, President Obama set a goal for the United States: Make sure that by 2020 we have the highest rate of college attendance of any country in the world.

NACAC believes that to be successful in college or career and technical education, students and their families need to be informed on how to best prepare for these postsecondary options. Such preparation includes information on curriculum planning, student financial aid, the college admission process, and career planning. High school students and their families are faced with high-stakes decisions that will affect the rest of the student's life, including their career and lifetime earning potential. With the right resources and training, a school counselor is the best source for this critical information for all students.

Recommendations

As educators dedicated to helping students make the transition to postsecondary education, NACAC members' leading policy priority is solving the college access crisis. In the 2011 appropriations process, two principles must be addressed to achieve this goal: (1) access to need-based financial aid for postsecondary education and (2) access to quality counseling on postsecondary preparation.

For Fiscal Year (FY) 2011 Appropriations for Departments of Labor, Health and Human Services, and Education, NACAC urges appropriators to support of the federal student aid programs, improve access to school counselors for all students, and fund loan forgiveness for service in areas of national need.

I. Support Federal Student Aid Programs

- **Provide funds to increase the Pell Grant Maximum to \$5,710.** NACAC requests that Congress meet the President's request of raising the Pell Grant maximum to \$5,710, a \$160 increase over the current level. At \$5,710, the Pell Grant will assist nearly 400,000 more students than last year, and over a million more than FY 2009.
- **Appropriate funding for LEAP at \$200 million.** This federal-state partnership program has been the foundation of state-matched grants since 1972, generating more than one billion dollars for about one million students each year. The Grants for Access and Persistence (GAP) component of LEAP will allow states to create robust partnerships with institutions of higher education, businesses, and philanthropic organizations to provide low-income students with the additional need-based grants; early intervention; and early assurance of aid eligibility that equals success.
- **Provide SEOG funding of \$1 billion.** The Supplemental Educational Opportunity Grant (SEOG) program provides up to an additional \$4,000 in grant assistance to Pell Grant recipients in order of need. By law, colleges and universities match one-to-three the federal SEOG funds, and often far exceed this matching level, multiplying the federal investment in low-income students.
- **Provide \$300 million in increased funding to Federal Work-Study.** The House jobs bill proposes to provide an additional \$300 million for the Federal Work Study program, because it has proven to be an efficient program, and effective investment to keep students employed and in college, rather than dropping out and getting in unemployment lines. The stimulus funds provided for FWS in 2009, provided jobs for an additional 162,000 students, who would have otherwise had to borrow more to stay in school.
- **Appropriate funding for TRIO at \$1 billion to prevent the loss of 200 Upward Bound programs, an unfunded mandate in Talent Search, and the continued stagnation of other TRIO programs.** Without the inclusion of \$57 million in additional discretionary funding, about 200 Upward Bound programs will be lost in academic year 2011-2012. Meanwhile, Talent Search programs will need \$35.8 million to enable just 15% of its students to receive services to support successful completion of rigorous secondary curricula, as mandated by HEOA. Finally, an additional \$57.2 million will allow for the restoration and expansion of the remaining TRIO programs (Educational Opportunity Centers, Student Support Services, Veterans Upward Bound, Upward Bound Math-Science, and McNair Postbaccalaureate Achievement).
- **Provide \$400 million in funds for GEAR UP.** GEAR UP provides early college awareness activities, tutoring, mentoring, academic preparation, and college scholarships to improve access to higher education for low-income students. This partnership program requires cooperation among K-12 schools, colleges, state higher education entities, businesses, and community-based organizations. By leveraging private matching resources to supplement the federal investment, GEAR UP significantly increases the number of low-income students who are prepared to enter and succeed in college.

Rationale: Need-based financial aid programs are the most successful federal college access programs. Appropriations for grant, work-study, loan and college access programs make postsecondary education a reality for low-income students. FY 2011 appropriations are critical to college access, persistence and completion of degrees by low-income students.

II. Improve Access to School Counselors for All Students

Appropriate funding for the Elementary and Secondary School Counseling Program (ESSCP) at \$55 million. The ESSCP's statutory language contains a funding trigger directing the Department of Education to award ESSCP grants only to elementary school programs unless the funding for ESSCP surpasses \$40 million. An appropriation of \$55 million will ensure that secondary school programs extend the benefits of ESSCP resources to our nation's middle and high school students.

There is a significant demand for federal assistance to build the capacity for school counseling programs in America. According to the American School Counselor Association, the recommended student-to-counselor ratio is 250 to 1, but in reality, the average student-to-counselor ratio now approaches 467 to 1. Every two years when the U.S. Department of Education requests applications for ESSCP, it receives approximately 500 applications. It also notes that the current funding level (\$55 million for FY 2010) limits its ability to fund programs, resulting in funding only about 10% of applicants. For the 2007-2008 school year, 97 school districts across 22 states were able to provide counseling services and supports through ESSCP. In 2009, 64 school districts, comprising more than 850 schools and more than 429,000 students across 29 states, obtained new grants to establish or expand school counseling programs and services.

Rationale: Many students do not have access to a school counselor in the critical secondary school years when postsecondary planning must happen. In addition, quality school counselors nationwide are overburdened with large student caseloads and non-counselor duties, both of which hinder their abilities to provide quality postsecondary advising.

The ESSCP is the only federal program exclusively designed to provide funds to hire school counselors and other school-based professionals that help eliminate barriers to learning. This small but effective program has only recently been appropriated sufficient funds to allow high schools to receive grants to hire counselors.

III. Fund Loan Forgiveness for School Counselors

Appropriate Funding for Loan Forgiveness for Service in Areas of National Need. The Higher Education Opportunity Act of 2008 authorized funding for five years of loan forgiveness for service in areas of national need. After completing each school, academic, or calendar year after August 14, 2008, eligible professionals may qualify for forgiveness of a maximum of \$2,000. Loan forgiveness will continue up to five years and for a maximum of \$10,000 in total loan forgiveness. NACAC's school counselor members employed full-time in a school that qualifies are eligible for loan forgiveness.

The Fiscal Year 2010 Consolidated Appropriations bill did not appropriate funding for this loan forgiveness program. The appropriation will determine availability, as forgiveness will be granted on a first-come, first-served basis while funding lasts.

Rationale: Loan forgiveness can be an incentive for effective school counselors to enter and continue employment in schools where they make a difference. In addition, student loan debt is at an all-time high. According to the Project on Student Debt, as the average student loan debt for the class of 2007 was \$20,098. Evidence of the need for this program is also demonstrated by NACAC member inquiries throughout the last year regarding the forgiveness process, eligible schools, and appropriation totals.

Conclusion

NACAC urges the House Subcommittee on Labor, Health and Human Services, Education and Related Services Appropriations to draft education appropriations that will provide students from the neediest socioeconomic backgrounds with access to need-based financial aid and quality school counseling. Funding grant, work-study, loan, college access, counseling, and service area loan forgiveness programs will increase America's rate of college attendance and secure our nation's economic future.

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The National Association for Public Health Statistics and Information Systems (NAPHSIS) welcomes the opportunity to provide this written statement for the public record as the Labor, HHS, Education and Related Agencies Appropriations Subcommittee prepares its FY 2011 appropriations legislation. NAPHSIS represents the 57 vital records jurisdictions that collect, process, and issue birth and death records in the United States and its territories, including the 50 states, New York City, the District of Columbia and the five territories. NAPHSIS coordinates the activities of the vital records jurisdictions among the jurisdictions and with federal agencies by developing standards, promoting consistent policies, working with federal partners, and providing technical assistance to the jurisdictions.

NAPHSIS respectfully requests that the Subcommittee provide the National Center for Health Statistics' (NCHS) National Vital Statistics System \$11 million in FY 2011—consistent with the President's request—to support the states and territories as they implement the 2003 birth and death certificates and electronic data collection systems.

Collection of birth and death data through vital records is a state function and thus governed under state laws. NCHS purchases birth and death data from the states to compile national data on vital events—births, deaths, marriages, divorces, and fetal deaths. These data are used to monitor disease prevalence and our nation's overall health status, develop programs to improve public health, and to evaluate the effectiveness of those interventions. For example, birth data have been used to:

- Establish the relationship of smoking and adverse pregnancy outcomes;
- Link the incidence of major birth defects to environmental factors;
- Establish trends in teenage births;
- Determine the risks of low birth weight; and
- Measure racial disparities in pregnancy outcomes.

Just as fundamentally, death data are used to:

- Monitor the infant mortality rate as a leading international indicator of the nation's health status;
- Track progress and regress in reducing mortality from the leading causes of death, such as heart disease, cancer, stroke, and diabetes;
- Document racial disparities; and
- Otherwise provide sound information for programmatic interventions.

Most recently, vital statistics have grabbed headlines with Amnesty International's report of increases in pregnancy related deaths.

Years of chronic underfunding at NCHS have threatened the collection of these important data on the national level, to the extent that in FY 2007, NCHS would have been unable to collect a full 12 months of vital statistics data from states. Had the Subcommittee not intervened with a small but critical budget increase to continue vital statistics collection, the United States would have been the first nation in the industrialized world to be without a complete year's worth of vital data. Countless national programs and businesses that depend on vital events information would have been immeasurably affected.

Since that time, the Subcommittee has continually supported NCHS's vital statistics cooperative with the states. NAPHSIS and the broader public health community deeply appreciate these efforts. This year, we are pleased the President is following the Subcommittee's lead in seeking to build a 21st Century national statistical agency, requesting a \$23 million increase for NCHS in FY 2011, including \$11 million targeted for the modernization of the National Vital Statistics System. This increase will support states as they upgrade their outdated and vulnerable paper-based vital statistics systems, addressing critical needs for activities that have been on hold or curtailed because of budget constraints.

As we make significant strides in implementing and meaningfully using health information technology, it is imperative that we similarly invest in building a modern vital statistics system that monitors our citizens' health, from birth until death. The requested \$11 million in funding will move us toward a timelier and more comprehensive vital statistics infrastructure where all states collect the same data and all states collect these data electronically. Two forms of birth and death certificates are in use by states—the older 1989 standard certificate and the newer 2003 standard certificate. This more recent birth certificate revision includes data on insurance and access to prenatal care, education level of parents, labor and delivery complications, delivery methods, congenital anomalies of the newborn, maternal morbidity, mother's weight and height, breast feeding status, maternal infections, and smoking during pregnancy, among other factors. The 2003 death certificate includes data on smoking-related, pregnancy-related, and job-related deaths.

Currently, only 75 percent of the states and territories use the 2003 standard birth certificate and 65 percent have adopted the 2003 standard death certificate. Many states continue to rely on paper-based records, a practice which compromises the timeliness and interoperability of these data. Jurisdictions that had planned and budgeted to upgrade their certificates and systems have seen funding for these projects erode as states face severe budget shortfalls. These jurisdictions need the federal government's help to complete building a 21st Century vital statistics system. The President's requested down payment will help in this regard, allowing all jurisdictions to implement the 2003 birth certificate and electronic birth record systems. Approximately \$30 million is needed to modernize the death statistics system; but the President's request of \$3 million is

nonetheless an important first step. However, we request that the Subcommittee not require a state-match for funds to modernize death certificates, as proposed by the President. NAPHSIS's members most in need of federal support have indicated that a state-match requirement would inadvertently prevent jurisdictions from applying for these funds. Indeed, if states had available funds to invest in system improvements they would do so.

As the historic Patient Protection and Affordable Care Act is implemented, the vital statistics purchased by NCHS from states are needed more than ever to track Americans' health and evaluate our progress in improving it. The President's request of \$11 million for the National Vital Statistics System will lead to vast improvements in data collection and further enable us to better compare critical information on a local, state, regional, and national basis. Without additional funding, a potential erosion of state data infrastructure and lack of standardized data will undeniably create enormous gaps in critical public health information and may have severe and lasting consequences on our ability to appropriately assess and address critical health needs.

NAPHSIS appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee. If you have questions about this statement, please do not hesitate to contact NAPHSIS Executive Director, Garland Land, at gland@naphsis.org or (301) 563-6001. You may also contact our Washington representative, Emily Holubowich, at eholubowich@dc-crd.com or (202) 484-1100.



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Introduction

Chairman Obey, Ranking Member Tiahrt, and Members of the Subcommittee:

My name is Dan Hawkins, and I am the Senior Vice President of the National Association of Community Health Centers. On behalf of community health centers and the more than 20 million patients served nationwide, as well as the volunteer board members, staff, and countless members of the health center movement, I want to thank you for this Subcommittee's unyielding support for health centers and your dedication to the health center mission of providing affordable, accessible primary health care to all Americans. In this time of enormous challenges, your faith in us and your support through the Recovery Act in 2009 and now through the historic passage of health care reform, will allow us to rise and meet these challenges and continue to excel. With your support, our cost-effective, high quality system of care will continue to expand, reaching 40 million Americans by 2015.

About Community Health Centers

Over the past forty-five years, the Health Centers program has grown from a small demonstration project to an essential element of our nation's primary care infrastructure.

Today, health centers serve nearly 8,000 communities and, thanks to your support, the Health Centers program has grown to serve more low-income and uninsured patients each year. Health centers currently serve as the family doctor and health care home for one in eight uninsured individuals, and one in every five low-income children. Health centers are helping their communities address a range of increasing (and costly) health problems, including

prenatal and infant health development, childhood obesity, chronic illnesses, mental health, substance addiction, oral health, domestic violence and HIV/AIDS.

Federal law requires that every health center be governed by a patient-majority board, which means care is truly patient-centered and patient-driven. Health centers must be located in a designated Medically Underserved Area (MUA), and must provide comprehensive primary care services to anyone who comes in the door, regardless of ability to pay. Because of these characteristics, the insurance status of health center patients differs dramatically from other primary care providers. As a result, the role of public dollars is substantial. Federal grant dollars, which make up roughly twenty-one percent of health centers' operating revenues on average, go towards covering the costs of serving uninsured patients and delivering care effectively to our medically underserved patients. Additionally, more than 40% of health centers' revenues are from federal insurance programs, principally Medicare and Medicaid. The balance of revenues come from State and community partnerships, privately insured individuals, and patients' payments, which are based on their income level.

Health centers have been pioneers in improving health care quality, particularly in the area of chronic disease management. Through the Health Resources and Services Administration's (HRSA) Health Disparities Collaboratives, health centers have worked to improve their delivery systems and to more effectively educate patients on the self-management of their conditions such as cancer, diabetes, asthma, and cardiovascular disease. Health centers participating in the Collaboratives overwhelmingly report that health outcomes for their patients have dramatically improved. Published studies have documented these outcomes, including one study on the Diabetes Collaboratives where evidence showed that over a lifetime, the incidence of blindness, kidney failure, and coronary artery disease was significantly reducedⁱ.

Health centers not only improve health and save lives, they also cost significantly less, saving the health system overall. In South Carolina, a study showed that diabetic patients enrolled in the state employees' health plan treated in non-CHC settings were 4 times more costly than those in the same plan who were treated in a community health center. The health center patients also had lower rates of ER use and hospitalization.ⁱⁱ In fact, literally dozens of studies over the past 25 years, have concluded that health center patients are significantly less likely to

use hospital emergency rooms or to be hospitalized for ambulatory care-sensitive conditions, and are therefore less expensive to serve than patients treated elsewhere.ⁱⁱⁱ A recent national study done in collaboration with the Robert Graham Center found that people who use health centers as their usual source of care have 41% lower total health care expenditures than people who get most of their care elsewhere.^{iv} Extrapolating this further, health centers saved the health care system \$18 billion last year alone.

Funding Background

Over the last decade, this Subcommittee has been at the forefront of expanding access to primary care in America through the Health Centers program expansion. This expansion effort brought access to care to millions who were previously medically disenfranchised. Since 2001, this Subcommittee has nearly doubled the investment in the Health Centers program. In that time, more than 3,500 new health center sites have been created, and more than 10 million new patients have gained access to care in a health center.

Impact of Health Reform

The passage of comprehensive health reform builds on this Subcommittee's efforts by envisioning yet another expansion of the Health Centers program over the next five years. The law creates a Community Health Center Fund containing \$11 billion in new funding for health centers over the next 5 years. We estimate this funding will also allow health centers to grow to serve 40 million Americans by the end of FY2015. This investment will ensure that as more Americans become insured, they will actually have a health care home in which to access care.

FY2011 Request

In order for the Community Health Centers Fund to have its intended impact, it is critical that the discretionary funding level of the Health Centers program at least meet the FY2010 level of \$2.190 billion. Keeping the discretionary funding base at least at the FY2010 level will allow the Community Health Centers Fund to be fully utilized to reach and serve new patients through new health centers, expanded medical, oral, behavioral, and pharmacy services at existing health centers, and to allow the continuation of desperately needed ARRA Increased Demand

for Services funding to health centers who have already expanded care to almost 2 million new patients over the last year.

Conclusion

At this historic moment for the health centers movement, I am deeply proud to be speaking for community health centers nationwide. I have personally seen the power of health centers to lift the health and the lives of individuals and families in our most underserved communities. As a VISTA volunteer assigned to south Texas in the 1960s, I was asked by the residents of the poor community I served to help improve access to health care and clean water, and assisted in the development of one of the country's first health centers. That health center is still in operation, and has expanded to serve more than 40,000 patients annually. The community empowerment and patient-directed care model we used in Texas still thrives today in every health center in America.

I know the very difficult funding decisions you are forced to make in this difficult appropriations season. However, health centers provide a true, documented value to the government and to all who benefit from their services. In light of the passage of health reform, health centers are ready to do our part to live up to the incredible trust that has been placed in us. With your support, we look forward to ensuring that the government's investment in reform translates into improved health and wellness for the nation.

¹ Huang, E, Zhang, Q, Brown, S. E.S., Drum, M, Meltzer, D, Chin, M. (2007). The Cost-Effectiveness of Improving Diabetes Care in U.S. Federally Qualified Community Health Centers. *Health Services Research*, 42,(6p1), 2174-2193

² Proser M. "Deserving the Spotlight: Health Centers Provide High-Quality and Cost-Effective Care." October-December 2005 *Journal of Ambulatory Care Management* 28(4):321-330

³ Rust G., et al. "Presence of a Community Health Center and Uninsured Emergency Department Visit Rates in Rural Counties." *Journal of Rural Health*, Winter 2009 25(1):8-16; Dobson D, et al. "The Economic and Clinical Impact of Community Health Centers in Washington State: Analyses of the Contributions to Public Health and Economic Implications and Benefits for the State and Counties." Dec 2008 *Community Health Network of Washington and Washington Association of Community and Migrant Health Centers*; McRae T. and Stampfly R. "An Evaluation of the Cost Effectiveness of Federally Qualified Health Centers (FQHCs) Operating in Michigan." October 2006 Institute for Health Care Studies at Michigan State University. www.fqhc.org; Falik M, Needleman J, Herbert R, et al. "Comparative Effectiveness of Health Centers as Regular Source of Care." January - March 2006 *Journal of Ambulatory Care Management* 29(1):24-35; Proser M. "Deserving the Spotlight: Health Centers Provide High-Quality and Cost-Effective Care." October-December 2005 *Journal of Ambulatory Care Management* 28(4):321-330; Politzer RM, et al. "The Future Role of Health Centers in Improving National Health." 2003 *Journal of Public Health Policy* 24(3/4):296-306; see also, e.g., Politzer RM, et al. "Inequality in America: The Contribution of Health Centers in Reducing and Eliminating Disparities in Access to Care." 2001 *Medical Care Research and Review* 58(2):234-248; Falik M, et al. "Ambulatory Care Sensitive Hospitalizations and Emergency Visits: Experiences of Medicaid Patients Using Federally Qualified Health Centers." 2001 *Medical Care* 39(6):551-56; Starfield, Barbara, et al, "Costs vs. Quality in Different Types of Primary Care Settings," *Journal of the American Medical Association* 272,24 (December 28, 1994): 1903-1908; Stuart, Mary E., et al, "Improving Medicaid Pediatric Care," *Journal of Public Health Management Practice* 1(2) (Spring, 1995): 31-38; [Utilization](#)

and Costs to Medicaid of AFDC Recipients in New York Served and Not Served by Community Health Centers, Center for Health Policy Studies (1994); Stuart, Mary E., and Steinwachs, Donald M., (Johns Hopkins Univ. School of Public Health and Hygiene), "Patient-Mix Differences Among Ambulatory Providers and Their Effects on Utilization and Payments for Maryland Medicaid Users," Medical Care 34,12 (December 1993): 1119-1137; Health Services Utilization and Costs to Medicaid of AFDC Recipients in California Served and Not Served by Community Health Centers, Center for Health Policy Studies/SysteMetrics (1993).

"NACHC and the Robert Graham Center. *Access Granted: The Primary Care Payoff*. August 2007. www.nachc.com/access-reports.cfm.



Statement of the

NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS
Washington, DC

Submitted for the record to the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

FY 2011 Appropriations for Programs at the Centers for Disease Control and Prevention

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Summary:

The National Association of County and City Health Officials (NACCHO) represents the nation's 2,800 local health departments (LHDs). These governmental agencies work every day in their communities to prevent disease, promote wellness, and protect the health of the entire community. **LHDs have a unique and distinctive role and set of responsibilities in the larger health system and within every community.** The nation depends upon the capacity of LHDs to play this role well.

The nation's current recession further diminishes the ability of LHDs to measure population-wide illness, organize efforts to prevent disease and prolong quality of life and to serve the public through programs not offered elsewhere. Repeated rounds of budget cuts and lay-offs in LHDs continue to erode capacity. A series of NACCHO surveys found that in 2008-2009, 23,000 jobs have been lost in LHDs, which represents a 15% cut in the local public health workforce.

LHDs continue to respond to increased challenges; including H1N1 influenza, an increasing incidence of chronic disease and outbreaks of foodborne illness during a time of growing budget challenges. To help maintain the stability of LHDs, the federal government should increase its investment in the following programs in FY11 appropriations: Public Health Emergency Preparedness, Advanced Practice Centers, Preventive Health and Health Services Block Grant, Healthy Communities and the Health Prevention Corps. Programs authorized by the health reform law should also be funded to the extent possible in FY11 appropriations.



Public Health Emergency Preparedness**NACCHO Request: \$1.152 billion (including pandemic influenza preparedness)****President's Budget FY11: \$758 million (Public Health Emergency Preparedness)****Emergency Supplemental Funds for H1N1 Influenza: \$1.3 billion****FY10 funding: \$761 million (Public Health Emergency Preparedness)**

The safety and well-being of America's communities is dependent on the capacity of their health departments to respond in any emergency that threatens human health, whether it is an act of bioterrorism, an influenza pandemic such as occurred in 2009-2010, or a natural disaster. The Centers for Disease Control and Prevention (CDC) has explicitly adopted an "all-hazards" approach to preparedness, recognizing that the capabilities necessary to respond to differing public health threats have many common elements.

NACCHO requests \$1.152 billion in funding for FY11, which reflects continued funding for local and state preparedness activities under the Pandemic and All-Hazards Preparedness Act along with additional support necessary to sustain the capabilities that were put into place in 2009 to respond to the H1N1 flu epidemic, made possible through \$1.3 billion in federal emergency supplemental funding.

With recent progress in nationwide preparedness and ongoing challenges, including the next flu season, now is not the time to reduce federal funding that helps health departments continue their progress and address new, emerging threats. Especially when local health departments are under great stress from the loss of 15% of their workforce over the last two years, the nation cannot afford to lose the gains made by recent federal investment in public health. A loss of readiness is inevitable if the level of federal investment is reduced.

The enhanced capabilities enabled by pandemic influenza supplemental funding in 2009 will improve the response to other potential epidemics of infectious disease. At the same time, continuous training and exercising of all health department staff so that they are all ready for the next emergency must continue. Incorporating pandemic influenza preparedness into the context of all-hazards preparedness is the most efficient use of limited resources and will fully enable maintenance of the current level of preparedness and flexibility to alter priorities as needed when other public health threats emerge.

Advanced Practice Centers**NACCHO Request: \$5.4 million****President's Budget: \$5.3 million****FY10 funding: \$5.3 million**

The mission of the Advanced Practice Center (APC) program is to promote innovative and practical solutions that enhance the capabilities of all local health departments to prepare for, respond to, and recover from public health emergencies. With locations in eight different geographic areas of the United States, the APC program supports and strengthens local health departments by developing and disseminating resources focused on helping them address gaps in local-level preparedness and improve responsiveness to address myriad health hazards. An increase in funding to \$5.4 million would allow the tools produced through this program to reach more local health departments.

Preventive Health and Health Services Block Grant**NACCHO Request: \$131 million****President's Budget FY11: \$102 million****FY10 funding: \$102 million**

Local health departments are leaders in efforts to stop preventable health threats from occurring. Obesity, heart attack and accidental injury are all examples of preventable health problems local health departments work on every day. The Preventive Health and Health Services (PHHS) block grant program is a longstanding source of funding for these efforts.

The increasing prevalence of costly and *preventable* chronic health conditions represents a threat to America's health and economy. According to the CDC, the medical care costs of people with chronic diseases account for over 75% of the nation's health care costs. The emerging epidemic of overweight and obesity is associated with \$117 billion in annual direct medical expenses and indirect costs, including lost productivity, which impairs our economic competitiveness during a period of severe economic decline. Increased funding of \$131 million in FY11 for the Preventive Health and Health Services Block Grant would allow local and state health departments to increase their efforts to focus on community priorities aimed at reversing the increase in preventable disease rates.

Healthy Communities**NACCHO Request: \$30 million****President's Budget FY11: \$22.4 million****FY10 funding: \$22.8 million**

The Healthy Communities program is dedicated to supporting local communities in implementing evidence-based interventions and policy, systems, and environmental changes necessary to help communities prevent chronic diseases and their risk factors.

To reverse unfavorable trends in the prevalence and health consequences of chronic diseases, communities work in collaboration with local health department leadership to address such issues as affordable and accessible healthy food options, safe places for physical activity, and the need for targeted strategies that address and reduce health disparities. Changes in the local environment facilitate healthy choices and go hand in hand with education about how to be healthier.

The Healthy Communities program mobilizes community leadership and resources to transform the local environments where people live, work and play to stem the growth of chronic disease. CDC anticipates the cumulative impact of the Healthy Communities program to reach more than 300 communities by FY 2011. With increased funding of \$30 million in FY11, more communities can be reached with this innovative program.

Health Prevention Corps
NACCHO request \$10 million
President's Budget: \$10 million

According to the President's budget, the Health Prevention Corps program will "recruit new talent into service for state and local health departments and provide the building blocks for creating a stronger, interdisciplinary workforce." These funds are meant to create a foundation for the program by establishing a management plan for staffing and program administration, convening stakeholders to establish the program framework, and developing a curriculum for Corps members. A shortage of public health professionals is a constant challenge for local health departments and this program will help to build a supply of new personnel offering their talents and skills to local communities.

Programs Associated with Health Reform

The Patient Protection and Affordable Care Act authorized a number of new programs that will be beneficial to public health and local health departments. The health reform law provides an opportunity to focus on maintaining and creating health through support of community prevention programs. The law also includes programs that will help to strengthen the public health workforce which was challenged by shortages even prior to layoffs and attrition caused by recent budget cuts. Programs such as Public Health Loan Repayment and Mid-Career Training grants, Epidemiological and Laboratory Capacity Grants, Community Transformation Grants, Healthy Living, Aging Well and the Diabetes Prevention Program would fill tremendous needs at the local level and should be funded to the extent possible in the FY11 appropriations process.

Statement of Sherry Black
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Submitted to the House Appropriations Committee
Subcommittee on Labor, Health and Human Services, and Education
May 19, 2010

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit this testimony in support of FY 2011 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, as amended and administered by the Corporation for National and Community Service (CNS). The National Association of Foster Grandparent Program Directors (NAFGPD) is a membership-supported professional organization whose roster includes the majority of more than 330 directors, who administer Foster Grandparent Programs nationwide, as well as local sponsoring agencies and others who value and support the work of FGP.

Mr. Chairman, I would like to begin by thanking you and the distinguished members of the Subcommittee for your steadfast support of the Foster Grandparent Program. No matter what the circumstances, this Subcommittee has always been there to protect the integrity and mission of our programs. Our volunteers and the children they serve across the country are the beneficiaries of your commitment to FGP, and for that we thank you. I also want to acknowledge your outstanding staff for their tireless work and the very difficult job they have to "make the numbers fit." – an increasingly difficult task in this budget environment.

FGP programs continue to face considerable stress in covering the rising costs of administering and maintaining quality programs. This situation is compounded by the current economic climate during which programs are in jeopardy of losing sponsors and raising local dollars is increasingly difficult. NAFGPD respectfully requests \$131,871,000 for the Foster Grandparent Program in FY 2011. This funding level for FGP would:

- Generate opportunities for some 1,386 new low-income senior volunteers to contribute 1,446,984 hours of service annually to nearly 6,000 additional children with special needs through competitive PNS expansion grants to existing FGPs.
- Provide a .35 cent stipend increase that would raise the stipend from \$2.65 an hour to \$3.00 an hour. Income eligible volunteers have not received a stipend increase since 2001.
- Provide a small administrative cost increase for all programs to help cover the staggering increases in administrative costs each is experiencing

FGP: AN OVERVIEW

Established in 1965, the Foster Grandparent Program was the first federally funded, organized program to engage older volunteers in significant service to others. It remains today the only

volunteer program in existence that enables seniors living on very low incomes to serve as community volunteers by providing a small non-taxable stipend that allows volunteers to serve at little or no cost to themselves. From the 20 original programs based totally in institutions for children with severe mental and physical disabilities, FGP now comprises 334 programs in every state and the District of Columbia, Puerto Rico, and the Virgin Islands. These programs are now primarily in community-based child caring agencies or organizations -- where most special needs children can be found today -- and are administered locally through a non-profit organization or agency and Advisory Council comprised of community citizens dedicated to FGP and its mission. FGP represents the best in federal partnerships with local communities, with federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. Through this partnership and the flexibility of the program, FGP is able to meet the immediate needs of the local communities. This was demonstrated by Foster Grandparent Programs in communities that were impacted by the influx of Hurricane Katrina evacuees. Foster Grandparents rallied to provide services to children in shelters, child care centers, and schools.

FGP: THE VOLUNTEERS

There are currently 38,400 Foster Grandparent volunteers who gave 24 million hours of service in their communities in FY 2009 to almost 250,000 children, including 5,400 children of prisoners. FGP is a versatile, dynamic, and uniquely multi-purpose program. The program gives Americans 55 years of age or older, who are living on incomes at or less than 200% of the poverty level, the opportunity to serve 15 to 40 hours every week and use the talents, skills and wisdom they have accumulated over a lifetime to give back to the communities which nurtured them throughout their lives. FGP provides intensive pre-service orientation and at least 48 hours of ongoing training every year to keep volunteers current and informed on how to work with children who have special needs.

FGP engages older people who are not usually asked to serve, those usually considered as needing services rather than being able to serve: FGP actively seeks out low-income seniors. We dare to ask them to serve, and we help them to develop the additional skills they may need to function effectively in settings unfamiliar to them, like public schools, hospitals, childcare centers, and juvenile detention facilities. Through their service, our older volunteers say they feel and stay healthier, that they feel needed and productive. Most importantly, they leave to the next generation a legacy of skills, perspective and knowledge that has been learned the hard way—through experience.

FGP: THE CHILDREN

Through our volunteers, FGP also provides person-to-person service to children and youth under the age of 21 who have special or exceptional needs, many of whom face serious, often life-threatening challenges. With the changing dynamics in family life today, many children with disabilities and special needs lack a consistent, stable adult role model in their lives. The Foster Grandparent is very often the only person in a child's life who is there every day, who accepts the child, encourages him/her no matter how many mistakes the child makes, and focuses on the child's successes.

Special needs of children served by Foster Grandparents include AIDS or addiction to crack or other drugs; abuse or neglect; physical, mental, or learning disabilities; speech, or other sensory disabilities; incarceration and terminal illness. FGP focuses its resources in areas where they will have the most impact: early intervention services and literacy activities. Foster Grandparents work intensively with these very young children to address their problems at as early an age as possible, before they enter school. Nearly one-half of FGP volunteers serve nearly 12 million hours annually addressing literacy and emergent-literacy problems with special needs children.

Activities of the FGP volunteers with their assigned children include teaching parenting skills to teen parents; providing physical and emotional support to babies and toddlers at-risk; helping children with developmental delays, speech, or physical disabilities develop social and self-help skills; reinforcing reading and mathematic skills; and giving guidance and serving as mentors to incarcerated or other youth.

FGP: THE VOLUNTEER SITES

The Foster Grandparent Program provides child-caring agencies and organizations offering services to special-needs children with a consistent, reliable, invaluable extra pair of hands **15 to 40 hours every week** to assist in providing these services.

FGP: COST-EFFECTIVE SERVICE

The Foster Grandparent Program serves local communities in a high quality, efficient and cost-effective manner, saving local communities money by helping our older volunteers stay independent and healthy and out of expensive in-home or institutional care. The value local communities place on FGP and its multifaceted services is evidenced by the large amount of cash and in-kind donations contributed by communities to support FGP.

CONCLUSION: The message is clear: 1) the population of low-income seniors available to volunteer 15 to 40 hours every week is increasing; 2) communities need and want more Foster Grandparent volunteers and more Foster Grandparent Programs. The Subcommittee's continued investment in FGP now will pay off in savings realized later, as more seniors stay healthy and independent through volunteer service, as communities save tax dollars, and as children with special needs are helped to become contributing members of society.

Mr. Chairman, in closing I would like to again thank you for the subcommittee's support and leadership for Foster Grandparent Programs over the years. The National Association of Foster Grandparent Program Directors believes that you and your colleagues in Congress appreciate what our low-income senior volunteers accomplish every day in communities across the country.



April 16, 2010

The Honorable David Obey
 U.S. House of Representatives Committee on Appropriations
 Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
 Washington, DC 20515

The Honorable Tom Harkin
 U.S. Senate Committee on Appropriations
 Subcommittee on Labor, Health and Human Services, Education and Related Agencies
 Washington, DC 20510

Dear Congressman Obey and Senator Harkin:

The National Association of People with AIDS (NAPWA) and VillageCare are submitting joint written comments on the appropriations for domestic HIV programs for federal fiscal year 2011. Overall, NAPWA and VillageCare believe that the President's request for FY 2011 spending on domestic HIV programs, while including some increases in funding, is insufficient to meet the needs of persons living with HIV/AIDS in this country. We urge you to increase funding for domestic HIV/AIDS programs in the fiscal Labor-HHS, Transportation/HUD and Financial Services bills for the upcoming fiscal year.

Founded in 1983, NAPWA is the first coalition of people living with HIV/AIDS in the world, as well as the oldest AIDS organization in the United States. NAPWA is a trusted, independent voice representing the more than 1 million people living with HIV/AIDS in America.

VillageCare is a community-based organization serving seniors, persons living with HIV and AIDS, and others who face chronic and disabling conditions. Founded in New York's Greenwich Village nearly 35 years ago, the not-for-profit organization developed some of the first care and program responses to the AIDS epidemic in the 1980s, and has created a number of innovative programs and services, including the first AIDS day treatment program in the country and the largest AIDS skilled nursing facility.

With more than 56,000 new HIV infections annually and the United States already having over 1.1 million people living with HIV, coupled with the rising cost of medical care and other services, we urgently need to allocate sufficient resources to address unmet care and treatment needs of persons living with HIV. It is estimated that 29 percent of persons living with HIV/AIDS in the United States are uninsured. The HIV epidemic also continues to have a disproportionate impact on communities of color and on low-income individuals.

For nearly a decade, the HIV epidemic in the United States has faced serious underfunding, as the previous Administration chose not to focus priorities on the nation's own HIV challenges. Increases in funding are desperately needed to make up for these years of neglect.

While passage of health care reform promises to contribute significantly to filling the gap in health coverage, the most critical provisions in the new law do not kick in until 2014. This means that over the next four years, there will be persons living with HIV who will have to wait for access to treatment that could save their lives.

During this gap in time, it is vital for Congress to act to fill the void in resources that would connect people to care.

We offer the following recommendations where Congress can move to address vital HIV care and treatment needs.

1. Increase funding in the Ryan White program by \$810.8 million, for total funding of \$3,101.5 billion.

This includes a breakdown of funding as follows:

- Part A – Increase of \$225.9 million for total of \$905 million
- Part B: Care – Increase of \$55.9 million for a total of \$474.7 million
- Part B: AIDS Drug Assistance Program – Increase of \$370.1 million for a total of \$1,205.1 million
- Part D - Increase of \$131 million for a total of \$337.9 million
- Part F: AIDS Education Training Centers – Increase of \$15.2 million for a total of \$50 million
- Part F: Dental – Increase of \$5.4 million for a total of \$19 million
- Part F: Special Projects of National Significance – Support funding of \$25 million (level funding)

In many regions of the country, financing through Ryan White is often the only means to pay for health care and supportive services for many persons living with HIV/AIDS. Unfortunately, the President's proposed funding for the Ryan White HIV/AIDS program was increased by only \$40 million, with many parts of the Ryan White program remaining flat-funded. Advocates in the HIV community have called upon the Administration to provide at least \$810 million in new resources to meet growing demand. The nation needs continued aggressive action if we are to close the gap in access to treatment and care that exists for many persons living with HIV. Ryan White programs serve approximately 577,000 low-income, uninsured and underinsured individuals each year. For many people living with HIV, Ryan White-funded programs are the sole lifeline to HIV care, treatment and services.

2. Support emergency supplemental funding in FY 2010 for the AIDS Drug Assistance Program (ADAP) in the amount of \$126 million.

Eleven states have waiting lists with over 850 people waiting to get access to life saving HIV medications. In addition, many states have greatly restricted the drugs covered by the ADAP and restricted eligibility so that fewer people qualify for ADAP benefits. Urgent, immediate emergency supplemental ADAP funding that would flow to these programs during the current fiscal year will help address this crisis.

3. Expand access to housing by increasing Housing Opportunities for People with AIDS (HOPWA) funding by \$75 million, for a total of \$410 million.

Access to safe and affordable housing is essential to improving individual health outcomes and promoting public health. Improved housing status is strongly associated with increased access and adherence to care and with lowered rates of HIV risk behaviors. Demand for AIDS housing far exceeds availability and increased HOPWA funding is needed to support efforts to address this critical component of the HIV care continuum. In the light of flat funding across many federal programs, the President's proposed HOPWA increase of \$5 million is far too small to make any meaningful impact on the rising numbers of persons who are without access to stable housing.

4. Increase efforts to respond to the disproportionate impact of HIV among communities of color by increasing funding for the Minority AIDS Initiative (MAI) by \$207.1 million, for total funding of \$610 million.

Targeted funding is urgently needed to address the huge disparities in HIV infection among communities of color. MAI funding improves access to culturally and linguistically appropriate outreach, education, prevention, care and treatment programs and services.

5. Support new investments in HIV prevention education by increasing funding at the Centers for Disease Control and Prevention (CDC) by \$878 million, for total funding of \$1,606 million.

A significant increase in funding of HIV prevention initiatives is needed to reduce the number of new HIV infections, which have remained unchanged at about 56,000 per year since 2001. State and local health departments and community based organizations need adequate resources to strengthen and expand HIV testing, outreach and prevention education programs.

6. Increase funding for AIDS research at the National Institutes of Health (NIH) by \$410 million, for total funding of \$3.5 billion.

A lack of sufficient funding for the NIH has slowed important research efforts aimed at ending the HIV/AIDS epidemic in the United States. To reverse this trend, funding increases are needed for the Office of AIDS Research at NIH.

7. Support the \$1.4 million in appropriations for National HIV/AIDS Strategy implementation, coordination, evaluation and monitoring.

The National Strategy will be unveiled this year and this appropriation will be needed to achieve its goals. As National HIV/AIDS Strategy implementation begins, Congress must renew this \$1.4 million appropriation, which is contained in the Financial Services appropriations bill. In each of FY 2009 and FY 2010, Congress appropriated \$1.4 million for the White House Office of National AIDS Policy to help fund the cost of developing a comprehensive national HIV/AIDS strategy.

VillageCare and NAPWA look forward to working with Congress and the Administration to find more resources to address the significant unmet need for HIV primary medical care and supportive services that exists across the United States. We and others in the HIV community were extremely pleased with the steps taken by the Obama Administration in the first year. The President has expressed and demonstrated leadership on behalf of the HIV community with such actions as the four-year extension of the Ryan White Care Act and ending the HIV travel ban.

At the same time, the federal budget for FY 2011 will need significant modification and additions if we are to fulfill the vision of the President and others to end the AIDS epidemic in the United States.

For more information, you may contact Matthew Lesieur, director of public policy for both NAPWA and VillageCare, at (212) 337-5601 or mlesieur@napwa.org or matthewl@vcny.org

Thank you.

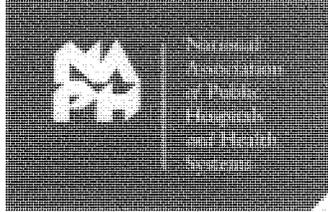
Sincerely,



Frank Oldham
President and CEO
NAPWA



Emma DeVito
President and CEO
VillageCare



Larry S. Gage
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**Testimony of Larry S. Gage
 President, National Association of Public Hospitals and Health Systems
 For Inclusion in the FY 2011 Public Witness Record**

**Committee on Appropriations
 Subcommittee on Labor, Health and Human Services, Education, and Related Agencies**

On behalf of the National Association of Public Hospitals and Health Systems (NAPH), which represents over 140 of the nation's largest urban safety net hospitals and health systems, I respectfully request that the Labor-HHS Appropriations Subcommittee support Congresswoman Wasserman Schultz's request for \$120 million in funding for the Community-Based Collaborative Care Network (CCN) program in FY 2011.

The CCN program was authorized by the recently enacted *Patient Protection and Affordable Care Act* (P.L. 111-148). The program, once funded, will provide grants to consortia of safety net health care providers—public or private nonprofit hospitals, community health centers, and others—to provide comprehensive, integrated, and coordinated care to low-income individuals and families. These vulnerable patients—low-income Medicaid beneficiaries and the uninsured—have a greater chance of unnecessarily suffering from poor health and uncontrolled chronic conditions due to fragmented care. The results are more sick days and decreased productivity at work as well as greater emergency room use and increased overall health care costs. With the passage of health reform, many of these patients will have access to coverage by 2014. A central impetus for the creation of the CCN program is the concern that the fragmented delivery system will not be prepared for these newly covered patients with health care needs that go beyond clinical care. Low income and vulnerable patients should be able to travel seamlessly within a network of health providers that understand their unique needs and work collaboratively to oversee care and improve health outcomes.

The goals of the CCN program are multi-faceted and include:

- Providing support for integrated delivery systems to coordinate the full range of care—from primary care to hospital and post-acute care—to low-income individuals and families, including those who may be newly covered under health reform;
- Providing mechanisms for improving both quality and efficiency of care for such vulnerable patient populations;
- Providing a range of necessary “wrap-around” support services for these populations that may not be needed by the rest of the population;
- Providing networks of safety net services for those individuals who may continue to fall through the cracks following implementation of health reform; and
- Providing ways under health reform to continue to ensure the availability of community-wide safety net services, such as emergency and trauma care, needed by everyone.

The CCN program will help prepare the delivery system for the influx of newly eligible Medicaid patients in 2014 and will provide vulnerable low-income uninsured individuals with a bridge to coverage.

Many safety net hospitals and community health centers already strive to provide vulnerable patients with a full spectrum of high-quality, coordinated health care. In fact, in some areas of the country, safety net providers have already created effective comprehensive care networks that improve quality and efficiency of care and provide necessary wrap-around services to the patients they serve. These networks offer a continuum of care that replaces episodic with comprehensive care and promotes control of chronic conditions like diabetes and asthma. Existing networks help reduce avoidable emergency room (ER) visits and uncompensated ER costs that jeopardize the financial viability of many safety net hospitals. By helping low-income patients adhere to aftercare instructions and arrive at follow-up visits, these networks can also reduce unnecessary hospital readmissions. Funding for CCNs in FY 2011 will help to prepare additional communities for the implementation of health reform by improving the coordination of safety-net providers throughout the country.

NAPH member hospitals and the safety net provider community know that CCNs uniquely hold the promise of improving care for vulnerable and low-income patients over the next several years. A fully funded CCN program is a logical bridge to coverage for many beneficiaries, helping to provide access in the near term and preparing the safety net for the eventual expansion in coverage. On behalf of NAPH’s member hospitals and the patients they serve, I respectfully request that the Labor-HHS Appropriations Committee appropriate \$120 million needed to set up the creation of CCNs in the upcoming fiscal year.

Below are a few examples of existing care coordination networks centered at NAPH-member institutions. A fully funded CCN program would enable these networks and others like them to expand services to more beneficiaries and would provide incentives for other safety net providers to establish similar networks.

*Examples of Ongoing Care Coordination Networks Operated by Safety Net Hospitals*Virginia Commonwealth University Medical Center

In Richmond, the Virginia Commonwealth University (VCU) Medical Center, a 779-bed teaching hospital, started the Virginia Coordinated Care for the Uninsured (VCC) program in 2000 to coordinate health care services for uninsured patients in the greater Richmond area. Prior to the VCC program, the VCU Medical Center provided all the services—primary and specialty—to any uninsured patient who presented at its facility. The VCC program expanded VCU Medical Center’s primary care capacity by providing patients with access to a community-based medical home and educated its patients on how to access appropriate health care services. During the first three years of the program, the VCU Medical Center saw a reduction in the number of emergency department visits and hospitalizations. Having invested over \$20 million in the VCC program since its inception, the VCU Medical Center estimates that annual cost savings are approximately \$3 million per year.

The VCC program is an innovative way of providing care to uninsured patients and the success of the program hinges on the VCU Medical Center’s ability to expand its primary care capacity. Rather than increasing its workforce and building new facilities, the VCU Medical Center partners with 50 community primary care providers (PCPs) from 40 practice locations to serve as the primary care medical homes for the patients in the VCC program. The VCU Medical Center pays these participating PCPs out of its own operating budget and the success of the VCC program depends on the Medical Center’s ability to continue to do so. The VCU Medical Center is currently searching for a more sustainable funding source for the VCC program so that these patients, who would otherwise be uninsured, will not be negatively impacted by uncertain economic conditions.

Jackson Health System; Memorial Healthcare System; North Broward Hospital District

In South Florida, three large public health care systems—the Public Health Trust of Miami-Dade County (Jackson Health System), Memorial Healthcare System (Hollywood, FL), and the North Broward Hospital District (Fort Lauderdale, FL)—formed the South Florida Community Care Network (SFCCN), a provider service network, in 1998 as part of Florida’s Medicaid waiver. The SFCCN facilitates the provision of integrated care to Medicaid patients and contains medical costs by removing the health plan and insurance company so that money flows directly from payer to provider. Because the SFCCN aligns incentives among the three public health care systems, these systems are able to coordinate and manage the care process and improve efficiencies. The state also spent less money on SFCCN patients than it would have spent for a comparable group of Medicaid beneficiaries, patient care improved as well; and is able to share the savings with the SFCCN.

Through the SFCCN, the safety net health systems in South Florida—Jackson Health System, Memorial Healthcare System, and North Broward Hospital District—manages the care of their Medicaid patients in an innovative and effective manner. For example, the SFCCN’s disease management component provides continuity of care to patients who would otherwise cycle on and off various state health programs. The success of the SFCCN—providing high quality care to Medicaid patients while at the same time containing the cost of care—should be promoted, especially as the viability of Medicaid programs in many states are being threatening by the current economic recession. As health reform implementation efforts ramp up, delivery models that utilize our existing capacity in a resource-conscious way, such as the SFCCN, should be encouraged. More demonstration projects, like the SFCCN, should be approved so that other safety net health systems have the tools and support to improve the coordination and management of the care provided to vulnerable populations.

Carolinas Healthcare System

In North Carolina, the Community Care of North Carolina (CCNC) initiative began in 1998 to manage the health care needs of Medicaid patients by focusing on primary care and improving the quality of care with a group management approach. The CCNC focuses on improving quality, utilization, and cost effectiveness of chronic illness care. There are 15 community-based networks with more than 3,500 PCPs that participate in the CCNC, providing 1,200 medical homes for about 750,000 Medicaid enrollees. As the key safety net provider in Western North Carolina and Northern South Carolina, Carolinas Healthcare System (CHS) is integral to the CCNC network it operates, managing the care of 100,000 Medicaid patients. Not only does CHS coordinate the care of its patients across the continuum of services, including well care, sick care, specialty care, and hospitalization services; support services are also provided from a team of care providers including social workers, interpreters, dietitians, pharmacists, and health educators. Patients have also benefited—93 percent of asthmatics received appropriate maintenance medications, resulting in 40 percent decrease in hospitalizations for asthma and 16 percent decrease in emergency department visits.

The CCNC initiative has been a success—not only do the patients receive better care, the CCNC also saves the state money. Since its inception in 1998, the CCNC’s operating costs range from \$8 to \$20 million per year. Starting in 2003, the CCNC has been saving the state at least \$200 million per year, compared with how much the state would have paid under the old fee-for-service model. Even compared to prior years, the CCNC saves the state anywhere between \$60 million to \$161 million from 2003 to 2006. The CCNC proves that adequate physician reimbursement is key to engage community PCPs, investing in community programs will reduce overall medical costs for all patients, and developing a local program that works can take time before savings are realized.

San Francisco General Hospital

Healthy San Francisco (HSF) is an innovative health care program designed to expand access to health services and deliver appropriate care to uninsured adults in San Francisco. HSF aligns the city’s existing health care safety net system—San Francisco General Hospital (SFGH), 27 primary care medical homes, and Community Behavioral Health Services—into a coordinated, integrated system to improve access to services and the delivery of care. SFGH provides all the

specialty care, emergency care, pharmacy, diagnostic, and inpatient services to participants of HSF; while the primary care medical homes provide primary and preventive care.

Participants of HSF pay a fee (based on their income) to enroll in HSF. SFGH, the 27 health centers, and Community Behavioral Health Services receive cost-based reimbursement from the San Francisco Department of Public Health, who assumes the financial risk for the cost of medical services provided to program participants. This program has improved access to care for uninsured patients who would otherwise have to navigate a scattered health care system.

Denver Health

Denver Health and Hospital Authority (Denver Health) is Colorado's primary safety net institution, providing medical care to residents of the entire state, and at least 25 percent of all Denver residents (or approximately 150,000 individuals in Denver). Denver Health is a comprehensive, vertically integrated organization with a 500-bed hospital that houses the only academic level I trauma center in the area; runs the 911 medical response system for the City and County of Denver; and operates an 8-clinic network of Family Health Centers throughout the city, a 12-clinic network of school-based health centers in Denver public schools, and the Denver Health medical plan. Linking all these components, Denver Health has a sophisticated information system that connects the billing, medical records, and patient scheduling functions. Through its integration along the continuum of care, Denver Health has been able to provide easily-accessible primary care—including obstetric care and dental care—and specialty care to the most vulnerable patients in Colorado.



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April 16, 2010

Chairman David R. Obey
Subcommittee on Labor, Health and Human Services,
Education and Related Agencies Committee on Appropriations
2358-C Rayburn House Office Building
Washington, D.C. 20515

Ranking Member Todd Tiahrt
Subcommittee on Labor, Health and Human Services,
Education and Related Agencies Committee on Appropriations
2358-C Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Obey and Ranking Member Tiahrt:

On behalf of the members of the National Association of School Psychologists (NASP), we are writing to thank you for holding hearings addressing *the FY2011 Budget* and for the opportunity to submit written testimony. We would like to submit for your consideration, these comments as NASP's written testimony on the proposal to eliminate dedicated funding for the Elementary and Secondary School Counseling Program and the Mental Health Integration Grants program.

NASP is the largest school psychology organization in the world and represents more than 26,000 school psychologists who are dedicated to increasing positive outcomes for children and adolescents. NASP promotes children's healthy learning and development through programs and services that strengthen the academic achievement, positive behavior, social-emotional learning, and mental wellness of all students, especially those who struggle with barriers to learning. School psychologists provide a broad array of services to general and special education students including: direct interventions such as counseling, interventions (academic, behavioral, and crisis), and social emotional skills development; assessment of student academic progress, and the assessment of cognitive, behavioral, and social-emotional needs; and consultation with parents, teachers and school administrators. School psychologists have specialized training in school systems, learning, child development, and mental health, as well as expertise in research-based strategies, data collection and analysis, and outcomes evaluation.

The U.S. Department of Education's "Blueprint for Reform: The Reauthorization of the Elementary and Secondary Education Act" offers a more comprehensive, meaningful focus on what is essential to helping all children learn to their fullest potential and is consistent with many

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of the guiding principles presented in the NASP document titled, *Ready to Learn, Empowered to Teach: Excellence in Education for the 21st Century*. (This document is available at: <http://www.nasponline.org/advocacy/readytolearn.aspx>.)

In particular, NASP strongly agrees with the Department that school climate and social-emotional learning are central to academic success and should be recognized as a key domain of school reform. Research and experience have long demonstrated that school engagement and student achievement improve when schools promote positive school climates, teach students interpersonal social skills and positive behavior, and support their emotional well-being. The proposed expansion of the mandate for the Office of Safe and Drug Free Schools (OSDFS) to foster successful, safe and healthy students is also essential to creating drug and violence free schools, strengthening student emotional wellness, and to promoting student achievement. We believe that meeting the needs of all students requires responding to the “whole child”, providing effective individualized instruction, ensuring inclusive and effective learning environments, and building genuine school-family-community collaboration.

NASP appreciates the Department of Education’s intention to improve administrative efficiency and foster innovation through changes in funding structures. However, we are deeply concerned about the proposed consolidation of funding for small and medium size programs that meet specific priority needs. Examples of these types of programs include the Javits Gifted and Talented Education program, the Elementary and Secondary School Counseling Program, Even Start, and the Mental Health Integration grants. These programs were created in response to public demand and the need to promote exemplary practices that are appropriate to the school setting, such as supporting student mental health. In most cases, the priorities of these programs clarify for school districts specific methods or models of improving practices and services to students.

Over the years, these programs have provided millions of dollars to State Education Agencies and local school districts struggling to provide sufficient student support funding for programs dedicated to remedying barriers to learning and improving student outcomes. NASP urges Congress to maintain the absolute priorities of these programs currently proposed for consolidation and to maintain or increase levels of funding for these programs’ priorities. To this end, NASP recommends that the Elementary and Secondary School Counseling Program (ESSCP) continue to be authorized with dedicated funding to support the current priorities for this program and that appropriations are increased to help meet the demand of the program.

The Elementary and Secondary School Counseling program (ESSCP) helps school districts to establish or expand school-based counseling services provided by qualified state licensed or certified school counselors, school psychologists, school social workers, or appropriately qualified psychiatrists and psychologists. The program helps improve school safety and increase mental health interventions. It is imperative that this program continue to be explicitly

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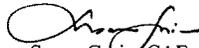
recognized and that the program's goals are prioritized for schools. Without this level of recognition, especially in a time of tightening budgets for school districts, it is possible that schools could lose sight of the importance of school counseling programs as sources for critical academic and social-emotional services for all students.

Additionally, with the passage of NCLB, Congress expanded the name of this program to include secondary schools. However, a funding trigger within the statute requires all funds up to \$40 million to be directed to elementary schools. In order for the services outlined in this program to respond to the growing needs of middle and high schools, the program must be funded at higher levels. There is a significant demand for the support provided by this program as evidenced by the number of applications received when the program is competed every two years. The existing level of funding is only able to provide support for roughly 10% of the applications received. Currently, ESSCP is funded at \$55 million; we respectfully request that funding for ESSCP increase to a minimum of \$80 million so that a significant effort can be made to meet the needs of elementary and secondary schools.

Furthermore, the OSDFS budget was cut drastically in FY 2009, leaving schools with fewer resources for school-based programs that support positive school climate or the mental health of students. These cuts also eliminated a formula-driven funding program eliminating the only dedicated funding source for schools to directly address this issue. We hope that the FY 2011 budget will be restore the funding for prevention programs in the Safe and Drug Free Schools program to the FY 2008 funding levels to ensure the necessary resources for both continuing and new initiatives to build this capacity.

Thank you for your careful consideration of this matter. If you have any additional questions, please contact our Director of Public Policy, Dr. Stacy Skalski at sskalski@naspweb.org or our Public Policy Fellow, Dr. Deitra Reiser at dreiser@naspweb.org.

Sincerely,


Susan Gorin, CAE
Executive Director



***United States House of Representatives
Appropriations Committee
Subcommittee on Labor, Health, Human Services and Education
May 18, 2010***

Written Remarks Submitted by:
National Association of Social Workers
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The National Association of Social Workers thanks Chairman Obey, Ranking Member Tiahrt, and the honorable members of the Subcommittee on Labor, Health, Human Services and Education for the opportunity to respectfully submit the following written remarks.

Background

The primary mission of the social work profession is to enhance human well-being and help meet the basic needs of all people, with particular attention to those who are vulnerable, oppressed, and living in poverty. Social work is essential to our society as it addresses psychosocial needs across the lifespan.

The National Association of Social Workers (NASW) is the largest professional association of social workers in the United States with chapters in each state and in Washington DC, Guam, Puerto Rico, the Virgin Islands, and an international chapter for U.S. social workers working abroad. NASW works to enhance the professional growth and development of its members, to create and maintain professional standards, and to advance sound social justice policies. As such, the NASW strives to be the voice for the full spectrum of professional social workers practicing in a diverse range of settings and roles. According to the last U.S. Census, there are over 600,000 professional social workers practicing in this country. We estimate that social workers in the U.S. touch 10,000,000 lives each day (Whitaker et al., 2006).

According to U.S. Substance Abuse and Mental Health Services Administration (2002), social workers are the largest mental health providers in the country with clinically trained professionals working with persons with emotional disturbances or serious mental illness, in times of relative calm and in times of serious crisis. There are more clinically trained social workers than clinically trained members of psychology, psychiatry and psychiatric nursing combined. Social workers are often the only providers of mental health services in rural areas.

One important aspect of the social work profession, and probably the best well known and understood, is that of a social safety net. Social workers are the frontline workforce of the health and social services delivery system, building the infrastructure of human capital for our country. They perform services that help people experiencing homelessness, poverty, addiction, violence, and mental and behavioral health crises. Social workers have long been the professionals who guide people to critical resources, counsel them on important life decisions, and help them reach their full potential.

With the current economic and social challenges, the social safety net has grown to include and protect a diverse group of people of all ages and walks of life. In addition to the traditional roles of child welfare and poverty alleviation, social work has become vital to the aging population that needs long term care, individuals struggling with addictions, and communities that are devastated by natural disasters, acts of terrorism, and violent tragedies. They work in hospitals, hospices, nursing homes, child welfare agencies, adoption agencies, prisons, schools, recovery clinics, in-patient psychiatric facilities, non-governmental organizations, and private mental health practice. Social workers direct foundations, corporations, colleges, and communities. They serve in the military, state legislatures, and most branches of government. Many social workers hold joint degrees in areas such as law, divinity, public health, pharmacy, and nursing.

Challenges

Although the services provided by social workers have become increasingly necessary, there is evidence that the current and projected supply of professional social workers cannot keep pace with demand. The NASW Center for Workforce Studies has found that there is already a shortage of social workers due to workforce challenges such as low salaries, high education debt, and serious safety concerns which are posing barriers to recruitment and retention to the profession.

Social work salaries are among the lowest for professionals in general and for those with master's level educations in particular. The NASW Center for Workforce Studies found that the median base pay for individuals completing the MSW as their highest degree is \$55,000. Those who did not progress beyond a BSW typically earn \$15,000 less than their colleagues with an MSW. Social workers who earn lower salaries are more likely to work in challenging agency environments and to serve more vulnerable clients. They are also more likely to leave the profession.

Educational debt is another major concern, as social workers with low salaries find it difficult to overcome this financial burden. Social work students, graduating with their master's degree from a public university can expect to accumulate over \$25,000 in educational debt. The U.S. Public Interest Research Group states that "37 percent of public 4-year graduates have too much debt to manage as a starting social worker." This makes a social work degree an impossible choice for many students. The profession should not be unattainable for the best and the brightest potential social workers because of high educational debt. The social work profession is personally fulfilling for many, however due to high loan debt and low income, many social workers struggle financially.

Retention of experienced social workers is a serious concern as the need, particularly in the areas of aging and child welfare, continues to grow. Social workers may be leaving the profession due to serious safety concerns. According to the American Federation of State, County, and Municipal Employees, 70 percent of case workers report that front line staff in their agency had been victims of violence or had received threats of violence. Social workers are considerably safer when measures such as global positioning systems, self-defense training, and conflict prevention are implemented.

Much like the nursing profession, in which the federal government previously invested, the social work profession cannot currently keep pace with increasing demand for services due to a confluence of factors. If these challenges are not addressed, the 10 million clients served by social workers every day will receive insufficient care and support.

During the War on Poverty, the United States government demonstrated its commitment to preserving the social safety net and to the social work profession. Today though, many of those social workers who served our country and benefited from that assistance are now preparing for retirement and the social work workforce is contracting.

The Bureau of Labor Statistics estimated the need for 595,000 social workers in 2006 and predicts that the need for social workers will increase to 727,000 social workers by 2016. In particular, the areas of aging, child welfare, mental and behavioral health, military and veterans' issues, health, education, and corrections will see a rapid increase in the need for professional social work services in the near future.

Conclusion and Recommendations

Recruitment and retention of social workers must be a focus of the federal government, schools of social work, and employers of social workers, or the profession will not be able to care for the millions of Americans who will require social work services. The social work profession is at a critical crossroads with society's psychosocial needs rapidly rising and recruitment and retention decreasing in the field, significant efforts must be taken to ensure a robust and competent workforce for the future. The challenges outlined above must be addressed or the millions of Americans requiring and receiving social work services may face compromised care. In response to these challenges, NASW makes the following appropriations report language recommendations:

Social Work Reinvestment Commission -- Congress recognizes the growing demand for a well-trained social work workforce to meet the most pressing needs facing our nation, such as veterans returning from combat zones with mental health crises, children suffering from abuse being permanently placed in safe homes, elders maintaining their independence in community settings, and ex-offenders reentering their communities with the tools necessary to succeed. The 600,000 social workers in the United States are the professionals who respond to these vulnerable populations. Concerned about workforce shortages and insufficient support for professional training, Congress directs the Secretary of Health and Human Services to establish a Social Work Reinvestment Commission to provide a comprehensive analysis of workforce trends and current gaps in incentives to recruit and retain professional social workers and to expand knowledge of evidence-based practices. There shall be 18 members of the Commission. Members of the Commission shall be appointed in consultation with the Committee. At least eight shall have experience in the field of social work. The Commission will report to Congress on long-term recommendations and strategies to maximize the ability of America's social workers to serve their clients with expertise and care. The Commission will report to Congress within 18 months of being established.

Social Work Research - The Committee recognizes that social work research informs practice and finds the solutions to some of society's most pressing problems. The NIH is urged to establish an Office of Social Work Research with the Office of the Director. The Office should stimulate and coordinate social work research activities, both across the NIH and with other Federal agencies. The NIH shall report to the Appropriations committee of the House and Senate on the progress achieved by this Office no later than September 30, 2011.

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**Testimony on FY 2011 Federal Funding for Addiction Treatment,
Prevention, Recovery Services and Research**

**Submitted to the House Appropriations Subcommittee on Labor, Health and
Human Services (HHS), Education and Related Agencies**

**The Hon. David Obey (WI), Chairman
The Hon. Todd Tiahrt (KS), Ranking Member**

Submitted by Robert Morrison, Executive Director

**National Association of State
Alcohol and Drug Abuse Directors (NASADAD)**

Regarding FY 2011 appropriations for:

*Substance Abuse and Mental Health Services Administration (SAMHSA), with a
focus on the Substance Abuse Prevention and Treatment (SAPT) Block Grant;
National Institute on Drug Abuse (NIDA), and
National Institute on Alcohol Abuse and Alcoholism (NIAAA).*

Chairman Obey, Ranking Member Tiahrt, members of the Subcommittee, on behalf of the National Association of State Alcohol and Drug Abuse Directors (NASADAD), and our component organizations, the National Prevention Network (NPN), and the National Treatment Network (NTN), thank you for your leadership on issues related to addiction. I am Robert Morrison, Executive Director of NASADAD. I am pleased to offer testimony regarding FY 2011 funding priorities.

Scope of the Problem: According to the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Survey on Drug Use and Health (NSDUH), approximately 23.1 million Americans aged 12 or older needed treatment for an alcohol or illicit drug problem in 2008. During the same year, only 2.3 million received treatment for a problem related to the use of alcohol or illicit drugs at a specialty facility. As a result, approximately 20.8 million people needed but did not receive services in 2008 in a specialty facility.

Substance Abuse Spending Represents a Tiny Fraction of All Health Expenditures: Substance abuse expenditures represented 1.3 percent of all healthcare expenditures in 2003 (\$21 billion for substance abuse compared to \$1,614 billion for all health expenditures). Using inflation adjusted terms, the growth rate for all health spending from 1993 to 2003 was 4.6 percent, while the growth rate for substance abuse spending during this same time period was 1.4 percent.

Yet Addiction is Associated with Many Other Diseases: In a 2004 study appearing in the Journal of the American Medical Association (JAMA), researchers examined “actual causes of death” defined by the Centers for Disease Control and Prevention (CDC) as factors that contribute to leading killers such as heart disease, cancer and stroke. The study identified nine leading “actual causes of death.” Tobacco, alcohol and illicit drugs – killing 530,000 Americans in 2000 – were three of the top nine. The others were diet/weight; microbial agents; toxic agents; motor vehicles; firearms and sexual behaviors.

Unaddressed Substance Abuse Problems are Costly: As noted in SAMHSA’s *National Expenditures for Mental Health Services and Substance Abuse Treatment, 1993-2003* (2007), when substance abuse spending was \$15.5 billion in 1998, the total economic costs of alcohol abuse were approximately \$184.6 billion and the total economic costs for drug abuse were \$143.4 billion (Harwood, 2000). These costs were linked not only to medical consequences of alcohol/drug use, but also crime, lost earnings, motor vehicle crashes, and more.

Financial Investments in Addiction Services Save Taxpayer Dollars: The National Institute on Drug Abuse (NIDA) notes that for every dollar spent on addiction treatment programs, there is an estimated \$4 to \$7 reduction in the cost of drug related crimes. With some outpatient programs, total savings can exceed costs by a ratio of 12:1 (NIDA InfoFacts, 2006).

Critical Need for Strong Systems of Care – Working Directly with State Substance Abuse Agencies: A vital concern of the Association is federal recognition of, and active support for, policies that promote strong State systems of care. State substance abuse agencies represent the best portal through which the federal government should work to affect addiction policy change and improvement at the community level. NASADAD members employ a number of mechanisms to ensure services are effective and efficient – including performance contracting and outcomes data management and reporting; contract monitoring; technical assistance; and more. State substance abuse agencies also promote and ensure quality through standards of care; patient placement criteria; training and other tools. Finally, NASADAD members represent the unit of State government responsible for designing, maintaining and sustaining a coordinated, State-wide system of care – a critical role given health reform implementation and our collective work to promote Recovery Orientated Systems of Care (ROSC).

Top Priority for FY 2011 – Increase Funding for Substance Abuse Prevention and Treatment (SAPT) Block Grant: NASADAD recommends \$2,008.5 million for the SAPT Block Grant in FY 2011– an increase of \$210 million over FY 2010 and the Administration’s FY 2011 request. Since 2007, as the economy and State budgets struggled, unemployment grew by 5.5 million. This is critical news for the SAPT Block Grant given that the 2008 NSDUH found unemployed persons need services at almost twice the rate as those with jobs: 18.8 percent of those who are unemployed compared to 10.6 percent of those who are employed need substance abuse services. An increase in SAPT Block Grant funds would help our public treatment system to better serve this increased need on the part of the low income and uninsured population.

Background - SAPT Block Grant: The SAPT Block Grant, a program distributed by formula to all States and territories, serves our nation’s most vulnerable, low income populations: those with HIV/AIDS, pregnant and parenting women, youth, and others. This vital program helps States and communities address their own unique needs – whether the primary problem is alcohol, methamphetamine or prescription drugs. The SAPT Block Grant represents, on average, approximately 40 percent of expenditures by State substance abuse agencies across the country.

SAPT Block Grant Funded Services Achieve Results: The SAPT Block Grant is an effective and efficient program that emphasizes accountability through the reporting of outcomes data. In particular, States have worked diligently with SAMHSA to implement the National Outcome Measures (NOMs) initiative. The SAMHSA/State partnership on NOMs promotes continuous quality improvement through a more systematic approach to data management and reporting. States now measure the impact of services on the use of alcohol and other drug use; employment; having stable housing; involvement with criminal activity; and efforts to live productively in the community. As noted by SAMHSA in its FY 2011 proposed budget, SAPT Block Grant funded programs in FY 2008 had positive results, where "...at discharge, clients have demonstrated high abstinence rates from both illegal drug (73.7 percent) and alcohol (78.2 percent) use."

In the Chairman's home State of Wisconsin, the Division of Disability, Elder Services, Substance Abuse and Mental Health reported 33,314 admissions to treatment in State Fiscal Year 2007 and noted the following outcomes in 2007 for those clients completing treatment: 73 percent were abstinent at discharge; 58 percent were employed full time at discharge; 95 percent had no criminal justice activity at discharge. For prevention, the Division reported that fewer students experimented with alcohol before age 13 (37 percent in 2003 vs. 24 percent in 2005/2006) and past month marijuana use decreased (22 percent in 2003 vs. 16 percent in 2005).

In the Ranking Member's home State of Kansas, the Addiction and Prevention Services Division within the Department of Social & Rehabilitation Services reported 15,980 admissions in State Fiscal Year 2008 and noted the following outcomes comparing admission to discharge: a 64.4 percent increase in abstinence from alcohol use; a 64.2 percent increase in abstinence from drug use; a 16.5 percent increase in employment; and a 4 percent decrease in homelessness. The Division served 227,180 persons with prevention services and noted the following outcomes cited by the Kansas Communities that Care Survey: decrease in past 30-day use of alcohol (31.3% in 2006 vs. 27.2 in 2008); cigarettes (12.1 % vs. 10.4%) and marijuana (8.6% vs. 7.8%).

Important Prevention Funding within SAPT Block Grant: Twenty percent of the SAPT Block Grant is dedicated to funding much needed substance abuse prevention services. In many States, set-aside funding represents a large source of prevention funds for the agency. Overall, SAPT Block Grant funding represents 64 percent of State substance abuse agency prevention funding. In 21 States, the set-aside represents 75 percent or more of the agency's prevention budget. A strong commitment to the SAPT Block Grant will ensure a strong commitment to much needed prevention services for our youth.

Recent History of SAPT Block Grant Funding: NASADAD is thankful that Congress provided an increase of \$20 million for the SAPT Block Grant in FY 2010. Overall recent trends, however, are problematic. To begin, funding was cut by more than \$20 million between FY 2004 and FY 2008. In addition, funding increases for the Block Grant over time have not come close to covering inflationary costs. Specifically, it is estimated that the 2010 SAPT Block Grant appropriation have need an increase of \$403.7 million simply to maintain services at 2004 levels [Data courtesy of the New York State Office of Alcoholism and Substance Abuse Services (OASAS) using the CPI-U as the proxy]. As a result, NASADAD views an increase of \$210 million as a down payment to make up for lost ground.

Center for Substance Abuse Treatment (CSAT): NASADAD recommends \$529.6 million in FY 2011, an increase of \$75 million compared to FY 2010 and \$42 million compared to the Administration's FY 2011 request.

NASADAD supports the proposed \$16.5 million increase in *Criminal Justice activities portfolio* that includes treatment drug courts, family dependency courts and re-entry programs. We request that State substance abuse agencies be eligible to apply for any program within this portfolio and that any non-State substance abuse agency applicant continue to be required to demonstrate extensive evidence of working directly and extensively with the State substance abuse agency. The Association also supports the \$8 million proposed increase to the *Screening, Brief Intervention, and Referral to Treatment (SBIRT)* program. The initiative helps grantees to (1) identify individuals with substance use problems; (2) intervene early before the conditions become severe; and (3) refer those who need specialty care to appropriate services. Grantee settings include trauma centers/emergency rooms, school clinics and other settings.

NASADAD opposes the planned cut of \$150,000 to the *Co-occurring State Incentive State Incentive Grant (Co-SIG)* program which helps States to increase capacity to provide coordinated and effective services for persons with co-occurring disorders. In addition, the Association opposes a proposed cut of \$190,000 to the *Pregnant and Postpartum Women (PPW)* which expands the availability of comprehensive, high quality residential treatment, recovery support, and family services for pregnant and postpartum women. Finally, NASADAD recommends restoration of the proposed cut of \$508,000 to the *Target Capacity Expansion (TCE) program* which provides critical funding for States to address gaps in service delivery.

Health Information Technology (IT): NASADAD also encourages a strong role for SAMHSA in helping promote web-based data systems given the important nature of health IT and the movement to establish standards and create electronic health records. The Association strongly supports the use of data to help improve services and outcomes. Further, State substance abuse agencies and providers alike acknowledge the complex issues the field faces in terms of implementation – especially given the passage of legislation pertaining to substance abuse and mental health parity legislation and health reform. As a result, NASADAD encourages the Administration to promote SAMHSA as an active and prominent leader of health IT matters – particularly those pertaining to the support of technical assistance and resources to State substance abuse agencies to help implement these important tools.

Center for Substance Abuse Prevention (CSAP): NASADAD recommends \$277.2 million, an increase of \$75 million compared to FY 2010 and an increase of \$54.2 million compared to the Administration's FY 2011 budget.

NASADAD strongly supports continued funding for the *Strategic Prevention Framework State Incentive Grant (SPF SIG)* program which is a five-step, data-driven public health planning model that utilizes evidence-based services to address areas of greatest need. The five steps of the SPF are (1) profile populations needs, resources and readiness to address the problems and gaps in service delivery, (2) mobilize and/or build capacity to address needs, (3) develop a comprehensive strategic plan, (4) implement evidence-based prevention policies, programs and practices and infrastructure development activities, and (5) monitor progress, evaluate effectiveness, sustain effective approaches and improve/replace those that fail. In all, 47 States have received SPF SIG awards. A key feature of the SPF SIG program is the State Epidemiological and Outcomes Workgroup (SEOW).

NASADAD applauds the proposed \$22 million increase for the *Partnership for Success Program*, which builds on the success of the SPF SIG. The purpose of the Partnerships for Success program is to help achieve a quantifiable decline in State-wide substance abuse rates. States receiving Partnerships for Success funds (1) leverage and coordinate State-wide prevention-related resources, leadership, technical

support and monitoring, (2) set measurable, need-based, State-wide performance targets for substance abuse prevention, and (3) partner with identified community coalitions to meet targets. Communities work closely with States to implement evidence-based programs, policies and practices, guided by the five steps of the Strategic Prevention Framework (SPF). The Partnerships for Success program also offers financial incentives (\$500,000) through a program expansion supplement to those grantees that meet or exceed performance outcomes goals by the end of year three of the five-year program.

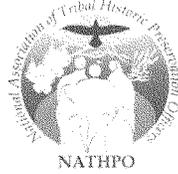
Promote Bridge Between State Substance Abuse Agencies and Federally Supported Community Health Centers: The proposed budget request includes \$25 million for the Health Resources and Services Administration (HRSA) to add “qualified and trained behavioral health counselors and other addiction specialists to enhance substance abuse care in federally supported community health centers.” The budget justification notes that HRSA will collaborate with SAMHSA on this initiative. In addition to being responsible for planning and implementing a comprehensive system of care, State substance abuse agencies maintain significant roles pertaining to workforce issues – including recruitment, retention, training, licensing/certification, etc. As a result, we urge Congress to shape this initiative to ensure that State substance abuse agencies are directly involved as a full partner in planning, implementing and overseeing the initiative.

Special Concern – Decrease in Overall Funding for Substance Abuse Prevention: NASADAD is extremely concerned about recent reductions in funding for substance abuse prevention. Resources available specifically for substance abuse prevention are dwindling. Some examples include:

- The Safe and Drug Free Schools—State Grants program was eliminated last year – resulting in a loss of approximately \$300 million in critical prevention funds.
- The President’s FY 2011 budget proposes to fund the Drug Free Communities at \$85.5 million – representing a cut of approximately \$10 million compared to FY 2010. The Association urges restoration of this cut in order to preserve core funding for substance abuse
- The President’s FY 2011 budget proposes to consolidate into one large flexible fund all Title V programs within the Department of Justice (DOJ) Office of Juvenile Justice and Delinquency Prevention (OJJDP). As a result, the \$25 million specifically set aside for the Enforcing Underage Drinking Laws (EUDL) program – a formula grant distributed to all States – would be eliminated. NASADAD is recommending that Congress maintain the EUDL program as a distinct initiative in order to ensure that all States have continued support for the enforcement of laws pertaining to underage drinking.

National Institute on Drug Abuse (NIDA): NASADAD recommends \$1,197.6 million for NIDA, representing an increase of \$137.8 million compared to FY 2010 and an increase of \$103.6 million compared to the Administration’s FY 2011 request. NASADAD wishes applaud NIDA for the collaborative work with NASADAD and the membership through its “Blending Initiative.” This work improves the translation of research into everyday practice.

National Institute on Alcohol Abuse and Alcoholism (NIAAA): NASADAD recommends \$522.4 million for NIAAA, representing an increase of \$60.1 million compared to FY 2010 and an increase of \$47.4 million compared to the Administration’s FY 2011 request. NASADAD would like to acknowledge the leadership of NIAAA on issues such as underage/childhood drinking.



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Testimony to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on the President's Fiscal Year 2011 Budget Request for the Institute of Museum and Library Services (IMLS)

The National Association of Tribal Historic Preservation Officers (NATHPO) is pleased to submit testimony for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on the President's Fiscal Year 2011 Budget Request.

The National Association of Tribal Historic Preservation Officers

NATHPO is a national not-for-profit membership association of tribal governments that are committed to preserving, rejuvenating, and improving the status of tribal cultures and cultural practices by supporting Native languages, arts, dances, music, oral traditions, cultural properties, tribal museums and cultural centers, and tribal libraries. NATHPO assists tribal communities protect their cultural properties, whether they are naturally occurring in the landscape or are manmade structures. In addition to members who serve as the Tribal Historic Preservation Officer (THPO) for their respective tribe, our membership includes many other tribal government officials who support our mission and goals. NATHPO provides technical assistance, training, timely information, original research, and convenes a national meeting of tribal representatives, preservation experts, and federal agency officials.

Priority Area – Institute of Museum and Library Services:

- A. Institute of Museum and Library Services
 - i. *Native American/Native Hawaiian Museum Services Program*
 - ii. *Native American Library Services: Basic Grants*
 - ii. *Native American Library Services: Enhancement Grants*
- B. National Endowment for the Arts; National Endowment for the Humanities

A. Institute of Museum and Library Services (IMLS)

i. The Native American/Native Hawaiian Museum Services Program

On September 24, 2003, President Bush signed Public Law 108-81, the Institute of Museum and Library Services (IMLS) Reauthorization Act, which contains a set-aside of 1.75% of all amounts appropriated to museums under the IMLS Act through Fiscal Year 2009 for the tribal museum grant program (Native American/Native Hawaiian Museum Services). The authorization provides for up to \$675,500 annually through Fiscal Year 2009 for a tribal museum grant program, or up to \$3.3 million total over the life of the authorization. The funding

i. The Native American/Native Hawaiian Museum Services Program, continued

can be used for "grants, contracts, or cooperative agreements" between IMLS and Indian tribes. To date, IMLS has awarded about \$4.8 million over five years to Native museums located throughout the country through a competitive grant program. Unfortunately, tribal interest in museums and cultural centers exceeds the current levels of support. With additional funds, more tribal cultural institutions would be able to receive larger grant amounts, thus serving a large, unmet need in Indian country.

Recommendations – Budgetary:

Increase the set-aside for the Native American/Native Hawaiian Museum Services grant program from 1.75% of the total Museum line item to 3.5% without any accompanying language that would cap the program.

ii. The Native American Library Services: Basic Grants

Under this grant program, federal funds are distributed in equal amounts among eligible applicants in a non-competitive process. The IMLS increased the Basic grant to \$6,000/Indian tribe per year and is available to support existing library operations and to maintain core library services. The Education/Assessment Option is \$1,000/Indian tribe per year and is supplemental to the Basic grant; it is also noncompetitive and must be requested. The purpose of the Education/Assessment Option is to provide funding for library staff to attend continuing education courses and training workshops on- or off-site, for library staff to attend or give presentations at conferences related to library services, and to hire a consultant for an on-site professional library assessment. Currently, one about one-third of the nation's 562 Indian tribes are participating in the Basic grants to libraries. The number of participating tribes dropped this past year as tribes were required to apply online using the www.grants.gov process. Related to the Basic grant program is the Enhancement program (described below), which is funded with the excess funds after the Basic grants have been awarded.

Recommendations – Budgetary:

1. The overall funding level of the Basic grant program needs to be increased because if all eligible tribal libraries requested an IMLS Basic grant, there would be no funds left over for tribal Enhancement grants. Increase the set-aside for the Native American Library Services grant program from 1.75% to 3.5% [of the overall Library funds] without any accompanying language that would cap the program.
2. Increase the individual Basic grant award to \$7,000/per Indian tribe per year.
3. Increase the Education/Assessment Option to \$3,000/per Indian tribe per year.

iii. Native American Library Services: Enhancement Grants

Funds for the tribal Enhancement grants support projects to advance the applicant's existing library services or implement new library services, particularly as they relate to the goals of the Library Services and Technology Act (LSTA). These competitive grants are intended to encourage the implementation of both mainstream and innovative library practices and under the current guidance and funding, only 13-15 tribal libraries are supported each year.

Recommendations – Budgetary:

Increase of the Basic library grants to American Indian/Native Hawaiian set-aside to 3.5%, so that funds are available for the Enhancement grant program, with an anticipated increase of tribal and village requests for Basic Grant and Educational Option funds.

iv. Directorate of the IMLS

Another identified issue is the need for a funded and prolonged effort to recruit and train staff to work in tribal libraries, archives, and museums. Recruiting and supporting Native people in these fields has been slow and needs a influx of attention and resources to make viable career options. Most Native communities are geographically challenged and are located in isolated communities, usually lacking access to the most current technology and infrastructure. Unfortunately, most of these communities do not offer the necessary education in library services and technology and museology. In the worldwide push to conduct work online, Indian country is being left behind in the technology age due to the lack of skilled workforce and lack of infrastructure in this important field (archives, libraries, and museums are an important component of records management in Indian country).

Recommendations – Administrative:

Create a Master of Library and Information Sciences (MLIS) service program, whereas an institution of higher education may offer financial assistance to Native students to assist with their educational costs and in return, the student will commit to working in a tribal library for three years after they receive their degree.

Recommendations – Budgetary:

Create a matching grant program where the Tribe and IMLS each support the salary of new Native American MLIS graduates, to work in the tribal library for three years after they've earned their degree through a pilot program supporting their educational costs.

B. National Endowment for the Arts (NEA) and National Endowment for the Humanities (NEH)

Both the National Endowment for the Arts (NEA) and the National Endowment for the Humanities (NEH) have exciting and positive programs, yet the challenge continues as to how Indian country participates and how traditional crafts, folklore-related activities, and tribal conservation efforts fit it to the existing grant programs. For example, NATHPO was able to write a successful grant application in the **Access to Artistic Excellence** program thus allowing NATHPO an opportunity to convene tribal museum directors for a weeklong seminar, but this program's availability is not widely known in Indian country. It is our understanding that there are many additional programs that may serve Indian country, but which rarely receive tribal applications. (Access to Artistic Excellence supports the creation and presentation of work in the disciplines of dance, design, folk and traditional arts, literature, media arts, museums, music, musical theater, presenting, theater, and visual arts and can include commissions, residencies, workshops, performances, exhibitions, publications, festivals, and professional development programs.)

Recommendations – Administrative:

The NEA and NEH host a national meeting with Indian country to discuss grant programs to which Indian tribes and Native Hawaiian organizations may participate. As part of this national meeting, challenges and barriers shall be identified by both the attendees and hosts so that in the future, Indian country may fully participate in the wide range of cultural activities the federal government supports and promotes. Discussion to include how NEA and NEH support Native language preservation and rejuvenation.



National Association of Workforce Boards

Where Business Helps America Work

FY 11 Public witness testimony for the record
House Labor-HHS Appropriations Subcommittee
Submitted by: Ron Painter, CEO
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Thank you for the opportunity to comment on the Administration's proposed 2011 budget. The National Association of Workforce Boards (NAWB) is a member association, among whose members are a majority of the 575 local employer-led Workforce Investment Boards and their nearly 13,000 employer member volunteers.

We write in support of the Administration's FY 11 overall appropriations request for the Training and Employment Services account under the Department of Labor. Adequate funding for the public workforce system has never been more critical. We are in the midst of the worst economic downturn in our lifetimes and the public workforce system has been stretched to its capacity, but continues to respond during this time of crisis.

Our employment crisis is not expected to ease in the foreseeable future. The annual Economic Report of the President released in February indicated that unemployment would remain above 8% through 2012. Federal Reserve Chairman Ben Bernanke was also pessimistic in his testimony before the Joint Economic Committee this past Wednesday about any large scale employment growth in the near term:

"As you know, the labor market was particularly hard hit by the recession. Recently, we have seen some encouraging signs that layoffs are slowing and that employment has turned up. Manufacturing employment increased for a third month in March, and the number of temporary jobs--often a precursor of more permanent employment--has been rising since last October. New claims for unemployment insurance continue on a generally downward trend. However, if the pace of recovery is moderate, as I expect, **a significant amount of time will be required to restore the 8-1/2 million jobs that were lost during the past two years.** I am particularly concerned about the fact that, in March, 44 percent of the unemployed had been without a job for six months or more. Long periods without work erode individuals' skills and hurt future employment prospects. Younger workers may be particularly adversely affected if a weak labor market prevents them from finding a first job or from gaining important work experience".

Workforce Investment Act programs have been on the front lines of assisting job seekers impacted by the recession. Over the past year, the Workforce Investment Act (WIA) system has seen over 7.6 million American workers turn to it for help in navigating the labor market

in search of jobs and/or the training individuals need to be competitive in their labor market. **This is a 60.2% increase in the number of people served through Employment and Training Administration programs over the previous year.** In comparison, 4.1 million workers were assisted during the same period the previous year.

Despite six job seekers nationally for every available job, those who received WIA services were likely to find jobs, with the likelihood increasing the higher the service level:

Performance Results

- **Workforce Investment Act Adult Program**
Entered Employment Rate 68.1%
Employment Retention Rate 83.3%
Average six months Earnings \$14,695
- **Workforce Investment Act Dislocated Worker Program**
Entered Employment Rate 70%
Employment Retention Rate 85.9%
Average six months Earnings \$16,304
- **Workforce Investment Act Youth Program**
Placement in Employment or Education rate 66.7%
Attainment of Degree or Certificate rate 58.2%

The ability of the public workforce system to maintain this level of success on behalf of job seekers and employers seeking skilled workers is incumbent upon the continuation of adequate funding. We encourage the Subcommittee to fund WIA formula programs at a minimum at the administration's request levels, as we expect to continue to face the challenges brought about by high unemployment for the foreseeable future.

Workforce Innovation Fund

We applaud the Administration's proposal for a \$322 million Workforce Innovation Fund. We believe that the state and local workforce boards have developed a host of promising practices since WIA was enacted in 1998, particularly in helping address the large numbers of persons dislocated during this recession or shut-out of the labor market due to a lack of appropriate skills. The Workforce Innovation Fund will allow local areas to engage with community partners and quickly scale effective practices on behalf of jobseekers in need.

However, we strongly urge the Subcommittee to fully fund the administration's request for WIA formula programs before allocating funding for the Workforce Innovation Fund, as these formula funds are essential to our ability to provide services to job seekers at the local level around the nation.

The protection of the WIA formula programs is particularly important this year with the diminution of the remaining workforce funding in the American Recovery and Reinvestment

Act, which have been heavily invested in providing training for job seekers. The bulk of these funds have been fully obligated at the local level, leaving little funding to commit for new trainees who seek services in the coming year. This funding “cliff” will provoke a large measure of frustration for individuals who are seeking services and are eligible, but for whom there are no funds available.

We suspect this is a well hidden policy issue since our current system of financial tracking counts expenditures but lacks the capacity to account for monies that are obligated by contract but not invoiced by the provider and paid by the fiscal agent.

Summer Youth employment

While our testimony is focused on FY 11 funding, we would be remiss if we did not express our appreciation for the Chairman’s inclusion of ARRA funding for WIA Youth programs which allowed 313,000 young people to have summer jobs last year who otherwise would not have been employed. Most of these ARRA funding for WIA Youth have been expended at this point, but local workforce programs are in the process of preparing for another expanded summer youth program with the limited funds they currently have available.

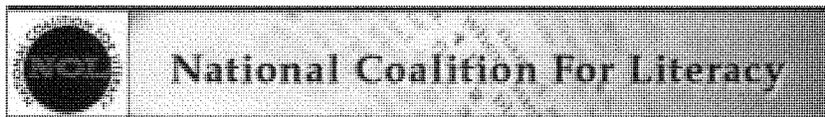
We greatly appreciate the Chairman’s inclusion of \$600 million for summer youth in the disaster relief bill passed before the Easter recess and hope that any emergency spending bill enacted this work period will include additional funding for WIA Youth programs to allow us to better address the looming crisis we are facing in youth employment this summer.

Policy Riders

NAWB would strongly encourage the committee to continue the policy riders that prohibit the redesignation of local areas or changes to the definition of administrative costs until WIA is reauthorized. There have been instances where there has been arbitrary action to reconfigure local areas and NAWB believes these riders will prevent any state v. local conflict until reauthorization.

We must continue to provide the support to the workforce system to help our jobseekers retool for employment in high demand sectors and maintain our global competitiveness.

Thank you for the opportunity to testify.



Testimony of

Dr. Peter Waite, President
On Behalf of the National Coalition for Literacy

Before the
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

April 16, 2010

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Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit to the Subcommittee the views of the National Coalition for Literacy on appropriations for adult education and family literacy, provided for under the Workforce Investment Act, Title II.

The National Coalition for Literacy represents 24 national organizations concerned about adult education and family literacy. We request a significant increase in funding and investment for adult education and family literacy in order to address critical, immediate needs, such as:

- **Clear waiting lists.** It would cost at least \$160M to clear existing waiting lists for instruction.
- **Increase access to adult English language learning programs.** Eleven million adults cannot communicate in English. We need to create more opportunities for immigrants to learn English by enhancing the capacity of current Adult Education and Literacy systems and programs.
- **Increase access to professional development.** Adult educators prepare adult learners for work and help transition them to vocational training and postsecondary opportunities; this requires quality professional development.
- **Improve professional quality of the adult education workforce.** 80% of teachers are part time; thousands are volunteers. We must create the conditions needed to attract and retain a full-time workforce.
- **Create a National Center for Adult Education, Literacy, and Workforce Skills¹.** A Center would address the continued need for research and innovation in our field.

While we ask for at least \$750 million for FY11, clearly it is not enough. These critical, urgent needs also require scaled investments that will provide adults important opportunities to retool and gain the skills they need to find family sustaining work.

Need and Demand for Adult Education

As you are aware, the 2003 National Assessment of Adult Literacy found that there are approximately 93 million adults in the United States who do not have the literacy skills to reach their full potential. Thirty million of those individuals have such low levels of literacy that it impedes their ability to fully function at home, at work, and in society. That is one in seven adults in our nation who can barely read a newspaper, a job application, a prescription label, or an election ballotⁱⁱ. Many live in poverty, experience complex health problems, and have extreme difficulty supporting their children's education. Eleven million adults cannot communicate in English.

The adult education system has the capacity to serve only approximately two and a half million of these 93 million adults each year. This takes into consideration combined federal, state and local funding complimented by philanthropic funding from a variety of sources. Nearly 90 million adults in need of adult basic and literacy education and English language acquisition go unserved.

Yet despite these startling facts, adult education has been nearly flat funded for a decade, seeing only a \$7M increase from 2001 – 2009ⁱⁱⁱ. The increase in FY09 to FY10 was a one time adjustment to correct for a funding calculation error that occurred from 2003-2008 and to hold states harmless so that they did not have to give funding back.

According to this year's Congressional Justification, the Administration built its budget request, in part, on 2006 waiting list data.^{iv} However, the National Council of State Directors of Adult Education has since published a March 2010 report, demonstrating that waiting lists and wait time have doubled in the last two years, during this economic crisis. Seventy-two percent of the programs reporting, from 50 of the 51 states and territories, confirmed waiting lists. Approximately *160,000 adults* want to access services but cannot.^v Additionally, community-based and volunteer literacy programs around the country report increased demand for services while traditional sources of funding are becoming more scarce.

The Congressional Justification also uses 2000 census data on high school dropouts to justify the proposed budget for adult basic and literacy education state grants, reporting an 11% dropout rate nationwide, a problem especially for some minority groups. Adult education programs serve as a key pipeline of education, catching these young adults and keeping them on course to a high school equivalent and on to a career or college enrollment. Adult education programs are well positioned to serve these young adults; programs are located not only in public school systems, but also in the community, libraries, and faith-based organizations. However, adult education programs can only serve these young adults to the extent which the nation invests in them.

Investing in Adult Education is a Workforce Investment

We commend the Administration for proposing to invest more through the Workforce Innovation Fund. Adult education is the best economic stimulus in which our country could invest. Adult education and job training can underpin economic recovery and open opportunities for low skilled workers by helping today's workforce develop the skills they need for both work and

community life. As literacy and educational attainment rise, so do adults' income and chances of stable employment.

According to the Bureau of Labor Statistics, unemployment decreases as education levels increase^{vi}:

| Unemployment rate in 2008 (Percent) | Education attained | Median weekly earnings in 2008 (Dollars) |
|-------------------------------------|---------------------------------|--|
| 2.0% | Doctoral degree | \$1,561 |
| 1.7 | Professional degree | 1,531 |
| 2.4 | Master's degree | 1,233 |
| 2.8 | Bachelor's degree | 1,012 |
| 3.7 | Associate degree | 757 |
| 5.1 | Some college, no degree | 699 |
| 5.7 | High-school graduate | 618 |
| 9.0 | Less than a high school diploma | 453 |

Note: Data are 2008 annual averages for persons age 25 and over. Earnings are for full-time wage and salary workers.

Source: Bureau of Labor Statistics, Current Population Survey.

Further, the Bureau of Labor Statistics estimates that by 2013, 90% of the fastest-growing jobs, 60% of all new jobs, and 40% of manufacturing jobs will require some form of postsecondary education. However, only 2% of the workforce need, at best, is met by high school graduates (3M graduates, 150M in the workforce)^{vii}. Thus, 94% of today's workforce will still be in the workforce in 2013; we must increase the skills of the *current adult workforce* for these high-demand jobs. Adult education is an important re-entry point for unemployed and underemployed adults who wish to raise their basic education skills or improve their English. However, these adults who want to become job and career-ready for these high-skilled, high-demand jobs are unable to get into instruction^{viii}.

Meeting the President's College Graduation Goal

The President has often restated his goal of the United States having the highest proportion of college graduates in the world by 2020. Yet, even if every state reached the same levels of high school graduation and college enrollment for high school graduates as the highest performing states, we would not reach this goal without a substantial effort to bring more adults who are out of school into postsecondary education. We must tap into the adult education pipeline if we are to close this college graduation gap and remain globally competitive.

English Language Acquisition

We must create opportunities for immigrants to learn English and civics by building and enhancing the capacity of current Adult Education and Family Literacy systems and programs. The population of workers and adult learners is changing dramatically. Between 1970 and 2005, the U.S. foreign-born population tripled to an estimated 35.8 million individuals, accounting for

12.4 percent of the country's population. In 2007 the Latino population was estimated at 44.3 million or 14.8% of the total population^{ix}. There are 14 million Asian Americans and nearly 1 million Pacific Islanders in the United States^x. At least 67% of the growth in the U.S. workforce in the past three years is comprised of new immigrants. It is estimated that between 2010 – 2030 first and second generation immigrants together will account for all the growth in the U.S. workforce^{xi}. According to U.S. Census Bureau estimates, nearly 1 in 5 adults in the U.S. speaks a language other than English at home, and more than 17 million speak English less than "very well."^{xii}

Investing in Quality

Increasing funds to clear waiting lists is a start. But if the adult education system is to serve the need, help prepare adults for 21st century jobs, transition adults to college, and meet or exceed performance goals, we must invest in quality of the profession as well as the numbers of learners served. The 21st century adult educator needs to:

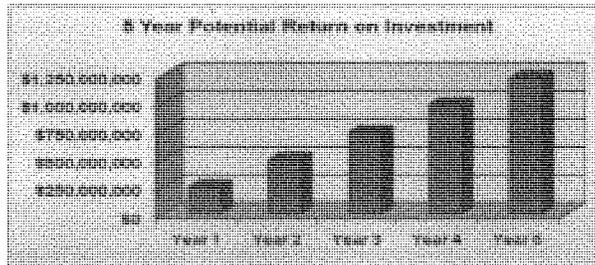
- Prepare adults to be digital age learners using existing and new technologies in creative ways.
- Prepare adults with the basic adult literacy and critical thinking skills they need to be competitive in the 21st century workforce.
- Teach adults with learning and other disabilities to close the life outcomes gap.
- Prepare adults to transition into postsecondary and vocational credit-bearing classes.
- Instruct a linguistically diverse classroom made up of learners at all different levels of language proficiency to improve their language proficiency.
- Increase political literacy and civic participation among our nation's adults.
- Strengthen programs to be scalable and flexible to meet new demands in communities.

However, only one in five adult education teachers are full time; thousands are volunteers; most are funded on year-to-year grant programs. Stable job status that facilitates a dedicated, professional workforce is critical to raising student achievement outcomes. Career ladders are virtually non-existent in adult education; a national credential in adult education does not exist. Many practitioners are not paid to attend professional development in order to meet these demands upon them. Developing the professional quality of the workforce is vital if we are to help adult learners achieve. We must increase access to professional development, provide opportunities for credentialing and career advancement, improve working conditions, and provide for research in professional development. Increasing appropriations will allow the field to do that.

Return on Investment

Adult education is a good investment. On January 21, 2010, the United States Department of Labor's Bureau of Labor Statistics reported that there was a \$9,828 wage differential for full time workers with a high school diploma (or GED) over those who did not graduate.^{xiii} The following is the potential return on investment for adults in 2008-2009 who received a GED in adult education programs. When looked at over a 5 year period, the original \$39,164,868 spent on the 165,637 GED students shows a potential return on investment of \$1,220,910,325 (3,017%).

| | |
|--|------------------------|
| Number of GEDs achieved in 2008-2009: | 165,637 ^{xiv} |
| Average dollars invested in student: | \$236.45 |
| Total: | \$39,164,868 |
| Number of GEDs achieved in 2008-2009: | 165,637 |
| Income differential: | \$9,828 |
| Total increase in taxable income per year: | \$1,627,880,436 |
| Federal tax rate: | 15% |
| Potential return on investment per year: | \$244,182,065 |
| One year return on investment: | 523% |
| Potential 5 year return on investment: | \$1,220,910,325 |



The current levels of funding have not and will not allow the field to grow to serve more adults, to improve and innovate practice, and meet existing and increasing demands. For these reasons, we strongly urge the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies to support a significant increase for programs provided by the Adult Education and Family Literacy Act, to at least \$750 million or more.

ⁱ NCL Proposal for a National Center for Adult Education, Literacy, and Workforce Skills http://www.ncladvocacy.org/NationalCenterPolicyPrinciples_FINAL.pdf

ⁱⁱ ProLiteracy www.proliteracy.org

ⁱⁱⁱ US Department of Education Budget History <http://www2.ed.gov/about/overview/budget/history/edhistory.pdf>

^{iv} Congressional Justification for Career, Technical, and Adult Education 2010 <http://www2.ed.gov/about/overview/budget/budget11/justifications/n-careered.pdf>

^v 2009 – 2010 Adult Student Waiting List Survey <http://www.ncladvocacy.org/2010AdultEducationWaitingListReport.pdf>

^{vi} Education Pays, Bureau of Labor Statistics http://www.bls.gov/emp/ep_chart_001.htm

^{vii} US Census www.census.gov

^{viii} Investing in the Adult Workforce <http://www.ncladvocacy.org/StateAlignmentInitiativesVolumell/InvestingInTheAdultWorkforce.doc>

^{ix} US Census: <http://www.census.gov/population/www/socdemo/hispanic/h006.html>

^x Language Spoken at Home, 2006 American Community Survey, U.S. Census Bureau

^{xi} Kirsch, I., Braun, H., Yamamoto, K. (2007) *America's Perfect Storm: Three Forces Changing Our Nation's Future*. Princeton, NJ: Education Testing Service

^{xii} U.S. Census Bureau (2003). *Language Use and English-Speaking Ability: 2000*. Washington, DC: Author

^{xiii} Bureau of Labor Statistics (January 2010). Retrieved February 16, 2010 from <http://www.bls.gov/news.release/wkyeng.nr0.htm>

^{xiv} Office of Vocational and Adult Education reporting website. Retrieved February 16, 2010.



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**Testimony of the National Coalition of STD Directors
Concerning the Public Health Budget for Fiscal Year 2011**

**Submitted for the Record to the House Appropriations Subcommittee on Labor,
Health and Human Services and Education
April 16, 2010**

The National Coalition of STD Directors is a nonprofit, nonpartisan association of public health sexually transmitted (STD) program directors in the 65 CDC directly funded project areas, which includes all 50 states, 7 cities and 8 U.S. territories. As the only national organization with a constituency that provides frontline STD services, NCSDDC is the leading national voice for strengthening STD prevention, research and treatment. These efforts include advocating for effective policies, strategies, and sufficient resources, as well as increasing awareness of the medical and social impact of STDs.

We appreciate this opportunity to provide the Subcommittee with information about the health crisis caused by the persistent and staggeringly high rates of STDs in the United States and about the programs of the Centers for Disease Control and Prevention (CDC) that combat these diseases.

The United States has the highest STD rates in the industrialized world, with more than 19 million people contracting an STD annually. In one year, our nation spends over \$8.4 billion to treat the symptoms and consequences of STDs. The indirect costs are higher, including lost wages and productivity, as well as human costs such as anxiety, shame, anger, depression and the challenges of living with infertility or cancer. The health consequences of STDs include: chronic pain, infertility, pregnancy complications, pelvic inflammatory disease, cervical cancer, birth defects and increased vulnerability to HIV, the virus that causes AIDS. Persons with a pre-existing STD have a 3 to 5 fold increased risk of acquiring HIV through sexual contact. In addition, studies have shown that HIV-infected persons who are also infected with other STDs are more likely to transmit HIV. Comprehensive STD treatment can reduce the likelihood of HIV transmission.

STDs have a disproportionate impact on young people, women, men who have sex with men (MSM) and racial and ethnic minorities. Of the approximately 19 million new STD infections each year, nearly half are among young people ages 15 to 24. Chlamydia, which leads to infertility, is the most frequently reported disease in the United States. Nearly 1 million women will have a severe case of pelvic inflammatory disease due to STDs. The transmission of STDs to babies -- prenatally, during birth or after -- can cause serious life-long complications including physical disabilities, developmental disabilities and death. Men who have sex with men (MSM) have historically experienced high rates of all STDs, including HIV/AIDS. In 2008, 63% of all primary and secondary syphilis cases were among MSM. The syphilis rate among males is now five times the rate among females, a dramatic disparity that did not exist a decade ago, when rates were nearly equivalent between the sexes. This trend suggests that the increase in cases among men have been primarily among men who have sex with men. Persons of color, particularly African-Americans, American Indians/Alaskan Natives, and Hispanics are also at higher risk of contracting STDs. In 2008, the rate of Chlamydia among African Americans was 9 times that of whites, for American Indian/Alaskan Natives it was 5 times higher than whites, and for Hispanics it was 3 times higher than whites. African American women experience syphilis rates 15 times higher than white women. Socioeconomic, cultural and linguistic barriers to quality healthcare and STD prevention and treatment services have likely contributed to a higher prevalence and incidence of STDs among racial and ethnic minorities.

While rates of STDs in this country have continued to skyrocket, federal funding for CDC's Division of STD Prevention has declined more than 22% since Fiscal Year 2003, when adjusted for inflation to 2009 U.S. dollars. For every dollar spent on STD prevention, \$43 is spent each year on STD-related costs. In addition, for every dollar spent on research, \$92 is spent each year on STD related costs.

The National Coalition of STD Directors requests an FY 2011 funding level of \$367.4 million, an increase of \$213.5 million, for the STD prevention, treatment and surveillance programs of the Centers for Disease Control and Prevention. These funds will significantly enhance the CDC's ability to reduce STD rates across the country.

Public Health Infrastructure (+\$33 million)

Federal funding for CDC's Division of STD Prevention has been relatively flat for the past 15 years. The combined effect of this, along with steadily increasing rates of STDs and more recently, dramatic state and local budget cuts due to the economic crisis, STD programs are in crisis mode and stretched thinner than ever. STD programs have had to cut staff, dramatically cut clinical services or close clinic doors altogether, and eliminate critical services such as free condom distribution programs. The public health infrastructure must be rebuilt and modernized. Investments in training, information and surveillance systems, public health laboratories, and better diagnostic technologies would increase efficiency, ensure program effectiveness and protect the health of future generations.

Public Health Workforce (+\$25 million)

A critical piece of rebuilding the public health infrastructure is scaling up the public health workforce. One quarter of the current public health workforce will be eligible to retire by 2012. We must invest now in training and retraining the next generation of public health professionals. This is particularly critical for STD programs. The underpinning of all STD programs is the Disease Intervention Specialist (DIS), who provide partner services to individuals infected with STDs, their partners, and to other persons who are at increased risk for STD infection. DIS are specially trained public health workers who are responsible for locating, counseling and coordinating the testing of individuals exposed to an STD. DIS complete an intensive CDC training course, which provides a strong foundation in field investigation techniques, both on the ground and on the internet. In some states, DIS also assist in the HIV Partner Services (PS) program, by assisting newly HIV-infected individuals with informing their partners of their status and encouraging those partners to seek HIV counseling, testing and related prevention services. DIS also provide surge capacity during an emergency response, such as the H1N1 outbreak. The versatile expertise of DIS make them indispensable during a public health crisis, but also highlight the need for increased resources to support the training and hiring of new DIS. The current economic crisis has forced many states to freeze the hiring of new DIS and even lay off DIS, in spite of increasing STD cases. Between 1999 and 2009, STD programs across the nation have experienced a 20% reduction in DIS staff.

Expand Chlamydia Screening and Infertility Prevention (+\$61.5 million)

Chlamydia is the most commonly reported disease in the United States, as well as the primary cause of infertility. The *Infertility Prevention Project* (IPP), a collaborative effort between CDC and Office of Population Affairs within HHS, has been working to reduce STD related infertility for 15 years. IPP provides funding to screen low-income women for chlamydia and gonorrhea in STD and family planning clinics. This project is a major success story in STD prevention, having been highly successful in reducing new cases of chlamydia and gonorrhea in areas where it has been implemented. However, additional resources are needed to bring this project to scale and reach a greater number of at-risk women. Chlamydia screening has also been shown to be extremely cost effective. Among 21 evidence-based clinical services recommended by the U.S. Preventive Service Task Force (USPSTF), chlamydia screening for young women ranked among the top 5 as having the most health benefits and best value for the dollar.

Additional federal resources would help support increased chlamydia screening in the public sector, expand school-based and correctional-based screening, as well as initiate a series of demonstration projects in the private sector aimed at increasing private sector screening rates.

Gonorrhea Control and Health Disparities Reduction (+\$40 million)

Gonorrhea is the second most commonly reported infectious disease in the U.S. African Americans are the most heavily impacted by this disease, with overall rates 20 times greater than that of whites in 2008. African American men aged 15 to 19 years old experience gonorrhea rates

40 times higher than white men in the same age group. An increasing issue of concern in the treatment of gonorrhea is antimicrobial drug resistance. In 2007, 14.6% of all gonorrhea cases demonstrated resistance, while 39% of the cases specifically among MSM demonstrated resistance. In 2007, CDC revised its gonorrhea treatment guidelines to include a single class of antibiotics.

Additional federal resources would be used to monitor antimicrobial resistant gonorrhea and test alternate or new drug regimens, initiate culturally competent social marketing campaigns, increase screening and partner services in hyperendemic areas, and develop demonstration research projects to determine the effectiveness and cost-effectiveness of gonorrhea prevention and control interventions.

Syphilis Elimination (+\$44 million)

The rates of primary and secondary syphilis, the most infectious stages of the disease, decreased throughout the 1990s, and in 2000 reached an all-time low. However, since 2000 as STD funding has declined, the syphilis rate in the U.S. has increased by 114%. Since 1999, the *Syphilis Elimination Effort* (SEE), a collaboration between CDC and state, local, and non-governmental partners, has worked to eliminate syphilis from all areas of the country and reduce long-standing health disparities. These strategies include: expanded surveillance and outbreak response activities, rapid screening and treatment in and out of medical settings, expanded laboratory services, strengthened community involvement and agency partnerships, and enhanced health promotion. These efforts have shown to be successful, but must be funded adequately. A 2008 study suggested that SEE funding in a given year was associated with subsequent declines (over the following two years) in syphilis rates in a given state. The greater a state's per capita syphilis elimination funding in a given year, the greater the decline in syphilis rates in subsequent years. While the activities of SEE have proven themselves to be effective, they must be adequately and consistently funded to ultimately eliminate this disease in the United States.

Additional federal resources for SEE would be prioritized for increased screening, particularly among HIV positive persons and pregnant women, the development and evaluation of rapid diagnostic tests, implementation of social marketing campaigns targeted towards men who have sex with men (MSM) and minority populations, and expanded screening in correctional facilities.

Build a Response to Viral STDs (Herpes, HPV, Hepatitis B) (+\$10 million)

Over 45 million Americans, almost 26% of the U.S. population, are infected with herpes simplex virus (HSV), a treatable but incurable viral STD. Improved treatment of HSV is fundamental to reducing the rates of transmission. Individuals with herpes are more susceptible to acquiring HIV. An estimated 20 million Americans are infected with human papillomavirus (HPV), the cause of about 90% of all cervical cancer cases. CDC would utilize additional funds to monitor the HPV vaccine introduction and behavioral impact of HPV vaccine through demonstration projects and an expansion of an existing, multi-level, multi-year behavioral research project. The most common source of hepatitis B virus (HBV) infection among adults is sexual contact.

Funding is needed to expand prevention efforts on HPV and HBV and to deliver education on the availability of preventive vaccines.

The National Coalition of STD Directors also supports the President's FY 2011 funding request of \$133.7 million for the Teen Pregnancy Prevention Initiative, within the Office of Adolescent Health (OAH).

We need to invest in programs that provide all of our young people with complete, accurate, and age-appropriate sex education that helps them reduce their risk of HIV, other STDs, and unintended pregnancy. In these tight budget times, we are pleased that the President's FY11 budget increased funding for the new teen pregnancy prevention initiative. However, by focusing the funding on teen pregnancy prevention, and not including the equally important health issues of STDs and HIV, we think the Administration has missed an opportunity to provide true, comprehensive sex education that promotes healthy behaviors and relationships for all young people, including LGBT youth. So many negative health outcomes are inter-related and we need to strategically and systemically provide youth with the information and services they need to make responsible decisions about their sexual health. We request that the teen pregnancy prevention initiative be broadened to address HIV and other STDs, in addition to the prevention of unintended teen pregnancy. We are pleased that the President's budget has once again included zero funding for failed abstinence-only-until-marriage programs and we encourage the Committee not to include funding for these ineffective programs.

We urge the Committee to substantially increase resources to protect our nation from the devastating consequences of STDs. The CDC has developed programs that have significantly reduced STD rates and the associated costs to society. We know how to prevent, control and treat sexually transmitted diseases; however, without additional funds, the CDC cannot establish these programs to scale in all 50 states, U.S. territories and directly funded cities.

**Testimony of the National Consumer Law Center, on Behalf of Our Low-Income Clients
Before the House Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies**

FY 2011 Appropriations for the HHS Low Income Home Energy Assistance Program

Prepared by Olivia Wein, Staff Attorney, National Consumer Law Center
(202-452-6252, owein@nclcdc.org)

The federal Low Income Home Energy Assistance Program (LIHEAP)¹ is the cornerstone of government efforts to help needy seniors and families avoid hypothermia in the winter and heat stress (even death) in the summer. LIHEAP is an important safety net program for low-income, unemployed and underemployed families struggling in this economy. The demand for LIHEAP assistance remains at record high levels. In FY 2010, the program is expected to help a record 9 million low-income households afford their energy bills, a 15% increase from the prior fiscal year. *In light of the crucial safety net function of this program in protecting the health and well-being of low-income seniors, the disabled, and families with very young children, we respectfully request that LIHEAP be fully funded at its authorized level of \$5.1 billion for FY 2011 and that advance funding of \$5.1 billion be provided for the program in FY 2012.*

Home Energy Bills Remain High at a Time When Unemployment and Underemployment is at Record High Levels

Residential heating expenditures remain at high levels. US average residential heating expenditures this winter are expected to be around the same for natural gas, about 24% higher for heating oil, 21% higher for propane, and 23% higher for electricity when compared to the five-year average for 2003-2008.² The years of steady, high energy bills are hitting low-income households struggling in this serious economic downturn. Low-income residential consumers, on average, pay a substantial amount of their income on residential energy, especially when compared to non-low-income households, 13.5 percent versus 3.6 percent, respectively.³ Because LIHEAP is targeted to the most vulnerable low-income households, LIHEAP recipient households have an average energy burden of 16 percent.⁴

The number of households that are struggling to make ends meet remains very high. According a Pew Economic Policy Group report, in March 2010 over 44 percent of the 15 million unemployed Americans had been unemployed for 6 months or longer.⁵ This is the highest rate of long-term unemployment since World War II. The “underemployment” rate in March 2010 is

¹ 42 U.S.C. §§ 8621 et seq.

² Derived from data in the Energy Information Agency, Short-Term Energy Outlook (March 2010), Table WF01.

³ US HHS, ACF, OCS, *LIHEAP Home Energy Notebook For Fiscal Year 2007*, June 2009 at Table A-3b. *Residential energy: Average annual expenditure, by amount (dollars) and mean individual burden (percent of income), for all, non low income, low income, and LIHEAP recipient households, by Census region and main heating fuel, FY 2007.*

⁴ *Id.*

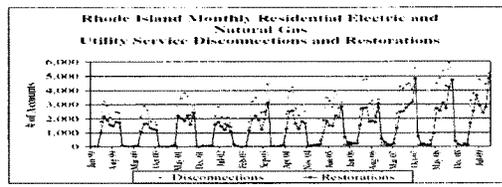
⁵ Pew Economic Policy Group Fiscal Analysis Initiative, *A Year or More: The High Cost of Long-Term Unemployment*, April 2010, Executive Summary.

16.9 percent.⁶ CBO's budget and economic outlook report projects that unemployment will average 9.5 percent in FY 2011.⁷ The hardship low-income households face is also apparent in the data below on the number of households falling behind.

States' Data On Electric and Natural Gas Disconnections and Arrearages Show That More Households Are Falling Behind

States are Predicting Record LIHEAP Participation: With the downturn in the economy, the states continue to experience record demand for LIHEAP assistance. NEADA reports that for FY 2010, 17 states have projected increases in participation of at least 20 percent, with **Mississippi** estimating a 68 increase, followed by **Washington** (42%), **Michigan** (38%), **Nevada** (34%), **New Jersey** (31%), **West Virginia** (28%), **Colorado** (26%), **Kansas** (25%), **New Hampshire** (25%), **Wisconsin** (25%), **Montana** (21%), **California** (20%), **Oregon** (20%), **South Carolina** (20%), **South Dakota** (20%), **Texas** (20%) and **Rhode Island** (20%).⁸ As jobs lag behind economic recovery, we fully expect the need for fully funded LIHEAP program in the states in FY 2011.

The steady and dramatic rise in residential energy costs has resulted in increases in electric and natural gas arrearages and disconnections. The National Energy Assistance Directors' Association reports that households experiencing natural gas shut offs increased from 4.1 million in 2008 to 4.3 million in 2009.⁹ The chart below of **Rhode Island** data is illustrative of the seasonal cycle of disconnections and restorations. It shows the alarming gap between service disconnections and reconnections has been increasing over time, suggesting increased length of service loss and greater numbers of households that do not regain access to service under their own accounts.



⁶ *Id.* Underemployment captures workers who became discouraged and stopped looking for work, older workers who opted to retire early instead of seeking work, young people delaying entering the work force and those workers who want full-time work, but have been forced to accept part-time work instead.

⁷ CBO, *The Budget and Economic Outlook: Fiscal Years 2010 to 2020*, January 2010 at Summary Table 2.

⁸ NEADA press release, *Record Numbers of Households Seek Assistance: States Call for the Release of Emergency Funds and Supplemental Assistance*, February 22, 2010. (hereinafter, NEADA Feb. 22, 2010 Press Release).

⁹ NEADA press release, *Record Number of Households Receive Energy Assistance: Shut-Offs Exceed 4.3 million Households in 2009*, December 18, 2009. See also Sandra Sloane, Mitchell Miller, Beverly Barker, Lisa Colosimo, "2008 Individual State Report by NARUC Consumer Affairs Subcommittee on Collections Data Gathering" (approved on Nov. 17, 2008 by the NARUC Consumers Affairs Committee). This national survey found that almost 40 million electricity and natural gas residential consumers held nearly \$8.7 billion in past due-accounts at the end of the 2007-2008 Winter heating season. The survey also concluded that in calendar year 2007, 8.7 million residential consumers had their electricity or natural gas service terminated for failing to pay their bills, with 3.6 million who remained disconnected as of May 2008.

Although there are winter utility shut-off moratoria in place in many states, not every home is protected against energy shut-offs in the middle of winter. As we approach the lifting of winter shut-off moratoria, we expect to see a wave of disconnections as households are unable to afford the cost of the energy bills. Low-income families are falling further behind as we endure year after year of rising home energy prices. We expect the disconnection peaks to grow and the gap between disconnections and reconnections to also grow, especially in light of the economic challenges faced by the unemployed and underemployed workers.

California: California has experienced a dramatic increase in LIHEAP participation from FY 2008 to FY 2010, with 166,000 households served in FY 2008; 434,000 in FY 2009 and projects serving 521,000 in FY 2010.¹⁰ The rise in the state's unemployment and foreclosure rates led the state Division of Ratepayer Advocates (DRA) to take a look at whether households are able to maintain access to natural gas and electric service. DRA found that low-income residential customers were experiencing a 19 percent increase in disconnections over the past year and that the disparity between low-income disconnections and non-low-income disconnections is the worst in three years.¹¹ In February 2010, the California Public Utilities Commission opened a docket to address electric and natural gas disconnections.¹²

Iowa: Iowa has experienced a steady increase in enrollment for the regular LIHEAP program from FY 2008 to FY 2010 with 85,000 households served in FY 2008; 95,000 in FY 2009 and 100,000 projected in FY 2010.¹³ The average monthly number of LIHEAP households in arrears in FY 2009 was 12 percent higher than the monthly average over the five-year period from FY 2004 through FY 2008. However, as a testament to the importance of LIHEAP, the average monthly number of all households in arrears in FY 2009 was 14 percent higher than the monthly average for all households in arrears over the previous five-year period.¹⁴

Ohio: Ohio has experienced a steady and dramatic demand for low-income energy assistance. The number of households entering into the state's low-income energy affordability program, the Percentage of Income Payment Program (PIPP), increased 6% from January 2009 to January 2010. The increase is an even more dramatic 98% between January 2003 and January 2010. The total dollar amount owed (arrearage) by low-income PIPP customers increased 5% from January 2009 to January 2010 and 118% when comparing PIPP customer arrears from January 2003 to January 2010.¹⁵ Ohio has experienced a steady increase in enrollment for the regular LIHEAP program from FY 2008 to FY 2010 with 387,000 households served in FY 2008; 394,000 in FY 2009 and projects 418,000 in FY 2010.¹⁶

¹⁰ NEADA Feb. 22, 2010 Press Release.

¹¹ California Division of Ratepayer Advocates, *Status of Energy Utility Service Disconnections in California*, November 2009, Executive Summary and pages 5 and 10.

¹² CPUC, *Order Instituting Rulemaking To Establish Ways to Improve Customer Notification and Education to Decrease the Number of Gas and Electric Utility Service Disconnections*, R.10-02-005, Issued February 5, 2010.

¹³ NEADA Feb. 22, 2010 Press Release and Iowa Bureau of Energy Assistance.

¹⁴ Based on data provided by the Iowa Bureau of Energy Assistance.

¹⁵ Public Utilities Commission of Ohio.

¹⁶ NEADA Feb. 22, 2010 Press Release.

Pennsylvania: Pennsylvania has also experienced a steady increase in enrollment for the regular LIHEAP program from FY 2008 to FY 2010, with 371,000 households served in 2008; 547,000 in FY 2009, and a projected 602,000 in FY 2010.¹⁷ Utilities in Pennsylvania that are regulated by the Pennsylvania Public Utility Commission (PA PUC) have established universal service programs that assist utility customers in paying bills and reducing energy usage. Even with these programs, electric and natural gas utility customers find it difficult to keep pace with their energy burdens. The PA PUC estimates that more than 21,029 households entered the current heating season without heat-related utility service. This number includes about 3,992 households who are heating with potentially unsafe heating sources such as kerosene or electric space heaters and kitchen ovens. In mid-December 2009, an additional 14,332 residences where electric service was previously terminated were vacant and over 7,438 residences where natural gas service was terminated were vacant. In 2009, the number of terminations increased 65% compared with terminations in 2004. As of December 2009, 18.2% of residential electric customers and 15.8% of natural gas customers were overdue on their energy bills.¹⁸

LIHEAP Is a Critical Safety Net Program for the Elderly, the Disabled and Households With Young Children

LIHEAP Is Vital To Poor Seniors: Poor seniors are cutting back on energy usage because it is not affordable. In general, elder households use less total household energy than non-elderly households, which is attributable primarily to the smaller dwelling units. But poor elderly households, on average, consume 12% more energy per square foot of living space (this measurement is also referred to as energy intensity) than non-poor elderly households. This disparity is attributable to the poorly weatherized living spaces and the use of old, inefficient heating equipment and appliances.¹⁹ LIHEAP is critical for helping low-income seniors maintain safe temperatures in their homes.

Dire Choices and Dire Consequences: Recent national studies have documented the dire choices low-income households face when energy bills are unaffordable. Because adequate heating and cooling are tied to the habitability of the home, low-income families will go to great lengths to pay their energy bills. Low-income households faced with unaffordable energy bills cut back on necessities such as food, medicine and medical care.²⁰ The U.S. Department of Agriculture has released a study that shows the connection between low-income households, especially those with elderly persons, experiencing very low food security and heating and cooling seasons when energy bills are high.²¹ A pediatric study in Boston documented an increase in the number of extremely low weight children, age 6 to 24 months, in the three months following the coldest

¹⁷ *Id.*

¹⁸ Pennsylvania Public Utilities Commission.

¹⁹ NCLC analysis of U.S. Energy Information Administration, 2001 Residential Energy Consumption Survey data on elderly energy consumption and expenditures.

²⁰ See e.g., National Energy Assistance Directors' Association, *2008 National Energy Assistance Survey*, Tables in section IV, G and H (April 2009) (to pay their energy bills, 32% of LIHEAP recipients went without food, 42% went without medical or dental care, 38% did not fill or took less than the full dose of a prescribed medicine, 15% got a payday loan). Available at <http://www.neada.org/communications/press/2009-04-28.htm>.

²¹ Mark Nord and Linda S. Kantor, *Seasonal Variation in Food Insecurity Is Associated with Heating and Cooling Costs Among Low-Income Elderly Americans*, *The Journal of Nutrition*, 136 (Nov. 2006) 2939-2944.

months, when compared to the rest of the year.²² Clearly, families are going without food during the winter to pay their heating bills, and their children fail to thrive and grow. A 2007 Colorado study found that the second leading cause of homelessness for families with children is the inability to pay for home energy.²³

When people are unable to afford paying their home energy bills, dangerous and even fatal results occur. In the winter, families resort to using unsafe heating sources, such as space heaters, ovens and burners, all of which are fire hazards. Space heaters pose 3 to 4 times more risk for fire and 18 to 25 times more risk for death than central heating. In 2007, space heaters accounted for 17 percent of home fires and 20 percent of home fire deaths.²⁴ In the summer, the inability to keep the home cool can be lethal, especially to seniors. According to the CDC, older adults, young children and persons with chronic medical conditions are particularly susceptible to heat-related illness and are at a high risk of heat-related death. The CDC reports that 3,442 deaths resulted from exposure to extreme heat during 1999-2003.²⁵ The CDC also notes that air-conditioning is the number one protective factor against heat-related illness and death.²⁶ LIHEAP assistance helps these vulnerable seniors, young children and medically vulnerable persons keep their homes at safe temperatures during the winter and summer and also funds low-income weatherization work to make homes more energy efficient.

LIHEAP is an administratively efficient and effective targeted health and safety program that works to bring fuel costs within a manageable range for vulnerable low-income seniors, the disabled and families with young children. **LIHEAP must be fully funded at its authorized level of \$5.1 billion in FY 2011 in light of high home energy costs and the increased need for assistance to protect the health and safety of low-income families by making their energy bills more affordable during this economic downturn. In addition, FY 2012 advance funding would facilitate the efficient administration of the state LIHEAP programs.** Advance funding provides certainty of funding levels to states to set income guidelines and benefit levels before the start of the heating season. States can also plan the components of their program year (e.g., amounts set aside for heating, cooling and emergency assistance, weatherization, self-sufficiency and leveraging activities).

²² Deborah A. Frank, MD *et al.*, *Heat or Eat: The Low Income Home Energy Assistance Program and Nutritional and Health Risks Among Children Less Than 3 years of Age*. AAP Pediatrics v.118, no.5 (Nov. 2006) e1293-e1302. See also, Child Health Impact Working Group, *Unhealthy Consequences: Energy Costs and Child Health: A Child Health Impact Assessment Of Energy Costs And The Low Income Home Energy Assistance Program* (Boston: Nov. 2006) and the *Testimony of Dr. Frank Before the Senate Committee on Health, Education, Labor and Pensions Subcommittee on Children and Families* (March 5, 2008).

²³ Colorado Interagency Council on Homelessness, *Colorado Statewide Homeless Count Summer, 2006*, research conducted by University of Colorado at Denver and Health Sciences Center (Feb. 2007).

²⁴ John R. Hall, Jr., *Home Fires Involving Heating Equipment* (Jan. 2010) at ix and 33. Also, 40% of home space heater fires involve devices coded as stoves.

²⁵ CDC, "Heat-Related Deaths – United States, 1999-2003" MMWR Weekly, July 28, 2006.

²⁶ CDC, "Extreme Heat: A Prevention Guide to Promote Your Personal Health and Safety" available at http://emergency.cdc.gov/disasters/extremeheat/heat_guide.asp.

WRITTEN TESTIMONY OF WANDA LIPSCOMB, Ph.D.
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NATIONAL COUNCIL FOR DIVERSITY IN THE HEALTH PROFESSIONS

PRESENTED TO THE

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION AND RELATED AGENCIES**

SUMMARY OF FISCAL YEAR 2011 RECOMMENDATIONS:

- 1) **\$300 MILLION FOR THE TITLE VII HEALTH PROFESSIONS TRAINING
PROGRAMS, INCLUDING:**
 - **\$33.6 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**
 - **\$35.6 MILLION FOR THE HEALTH CAREERS OPPORTUNITY
PROGRAM**

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wanda Lipscomb, President of the National Council for Diversity in the Health Professions (NCDHP) and the Director of the Center of Excellence for Culture Diversity in Medical Education at Michigan State University. NCDHP, established in 2006, is a consortium of our nation's majority and minority institutions that once house the Health Resources and Services (HRSA) Minority Centers of Excellence (COE) and Health Careers Opportunities Programs (HCOP) when there was more funding. These institutions are committed to diversity in the health professions. In my professional life, I have seen firsthand the importance of health professions institutions promoting diversity and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our nation and evaluate our needs over the next ten years. I want to say that minority health professional institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our nation's most medically underserved communities. Furthermore, our nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15% of the U.S. population, only 2-3% of the nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help NCDHP continue our efforts to help provide quality health professionals and close our nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the federal government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. **Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.**

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who

serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals, like the NCDHP members, have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 (FY06), FY07, and FY08. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating. We have been pleased to see efforts to revitalize both COE and HCOP in recent fiscal years, but it is important to fully fund the programs at least at the FY 2004 level so that more diversity is achieved in our health professions.

Earlier this year with the passage of health reform, the Congress showed the importance of the many of the Title VII programs, including the Minority Centers of Excellence (COE) and Health Careers Opportunities Program (HCOP), by reauthorizing the programs.

Minority Centers of Excellence: COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. *For FY11, I recommend a funding level of \$33.6 million for COEs.*

Health Careers Opportunity Program (HCOP): HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. *For FY11, I recommend a funding level of \$35.6 million for HCOPs.*

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, NCDHP member institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the

institutions and programs that have been **proven to work**. NCDHP seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

**STATEMENT FOR THE RECORD
OF THE
NATIONAL COUNCIL OF SOCIAL SECURITY
MANAGEMENT ASSOCIATIONS
Joe Dirago, President
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**Submitted to the
United States House of Representatives Appropriations Committee
Subcommittee on Labor, Health and Human Services, and
Education, and Related Agencies
April 16, 2010**

FY 2011 Funding for the Social Security Administration

On behalf of the National Council of Social Security Management Associations (NCSSMA) thank you for the opportunity to express our views and recommendations regarding the FY 2011 funding for the Social Security Administration. I am the President of NCSSMA. I have been the District Manager of the Social Security office in Newburgh, New York for eight years and have worked for the Social Security Administration for 30 years. On behalf of our membership I am pleased to have the opportunity to submit this written statement for the record to the Subcommittee.

NCSSMA is a membership organization of approximately 3,400 Social Security Administration (SSA) managers and supervisors who provide leadership in 1,262 Field Offices and 35 Teleservice Centers throughout the country. We are the front-line service providers for SSA in communities all over the nation. We consider our top priority to be a strong and stable Social Security Administration, one that delivers quality and prompt community based service to the people we serve, your constituents.

We are very appreciative of the support that the Subcommittee has provided for SSA's funding in recent years. The additional funding SSA received in Fiscal Years 2008 - 2010 helped significantly to prevent workloads from spiraling out of control and assisted with improving service to the American public.

We are very supportive of the President's FY 2011 budget request for the Social Security Administration (SSA). The total SSA budget request is \$12.528 billion, which includes \$12.379 billion in administrative funding through the Limitation on Administrative Expenses (LAE) account. We respectfully request that you provide at least the full President's budget request for SSA in FY 2011.

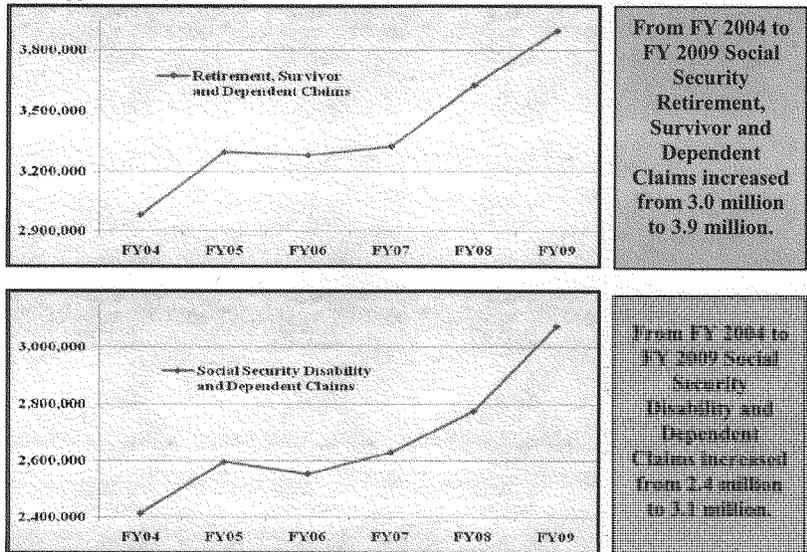
We are certainly concerned about the tremendous challenges facing SSA. We wholeheartedly agree with Commissioner Astrue's statement that it is a moral imperative that the disability backlogs be eliminated. On a daily basis, employees in our offices speak to thousands of individuals who are desperate to receive a decision on their claims for disability benefits.

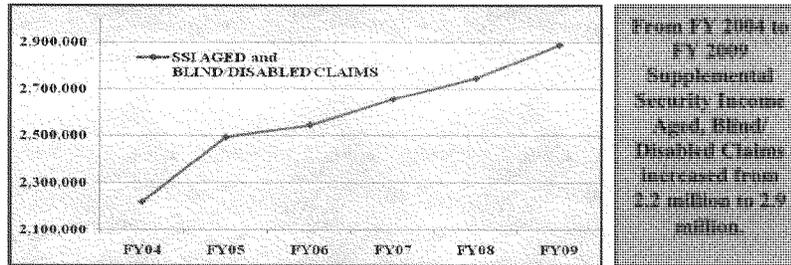
The additional funding SSA has received in recent fiscal years is definitely making a difference. For example, through March 2010, the number of pending hearings has dropped over 73,000 cases or nearly 10%. The average processing time for hearings is now 437 days which is the lowest it has been since December 2004.

Even though this is positive news, the Hearing Offices are now facing a significant wave of new hearings that are being filed, as a result of the increased disability claims resulting from the economic downturn. This fiscal year to date, the number of new hearings coming in is up 7.2% over FY 2009 and 13.1% over FY 2008. On an annual basis this will equal 44,795 more cases in Fiscal Year 2010 over Fiscal Year 2009 and 78,043 cases over Fiscal Year 2008.

Of greater concern is that in March 2010 the number of new hearings increased by over 8.5% compared to February 2010. This increase in hearings is expected to continue because of the significant number of disability claims filed as a result of the economic downturn. The rise in disability claims filings has also created backlogs in the State Disability Determination Services (DDSs). At the end of March 2010 the number of pending initial disability claims was 784,402, which is 227,732 more than at the end of FY 2008, a 41% increase. The number of disability reconsiderations pending in the DDSs is also rising rapidly. At the end of March 2010 there were 179,862 reconsiderations pending, which is 64,803 above the end of Fiscal Year 2009, a 56% increase. This increase foreshadows the second wave of cases coming to the Hearing Offices.

All of these workloads are flowing through SSA's Field Offices as well. The following charts detail how Field Offices have experienced a steady increase in retirement, survivors, disability, and Supplementary Security Income claims.





Field Offices are faced with the following additional workloads and challenges:

1) **Hearings Reversals Impact on Field Offices**

- The FY 2011 budget request provides for completing 73,000 more disability hearings.
- With the emphasis on eliminating the backlogs in ODAR, Field Offices continue to see a significant increase in the ALJ reversal workload.
- Because final processing of this high priority workload is completed in Field Offices, there is a clear resource implication for Field Offices.

2) **Impact of eServices Claims on Field Offices**

- The agency goal for FY 2012 is to process 50% of retirement applications and 25% of disability claims via the Internet.
- While eServices has assisted many Field Offices significantly with the high number of applications received, Field Office staff must still spend significant time processing many of these electronically initiated actions.
- Virtually all disability Internet applicants must be recontacted to perfect the application and to determine if the claimant wants or needs to also file an SSI application.
- Many retirement and survivor applicants must be recontacted to clarify issues or gather more information.

3) **Additional Field Office Customers and Increased Waiting Times**

- We have had five weeks with over 1 million visitors already this calendar year compared to only two weeks in all of 2009.
- Field Offices are diverting staff from the telephones to provide service to visitors to reduce waiting times.
- In the February 2010 NCSSMA Survey of Management, 71.7% of the respondents said they frequently or very frequently reassign staff from handling phone calls to helping at reception in an effort to reduce waiting times.

4) **Improving SSI Quality**

- According to a November 2009 OMB report, SSA paid out approximately \$45.0 billion to SSI recipients in FY 2009. However, there was an improper payment rate of \$5.436 billion or nearly 12.1% -- one of the largest in the Federal government.
- In the February NCSSMA 2010 Survey of Management, 82.5% said the number of case reviews done in their offices was not adequate to ensure that the work product was accurate.

- Of those that responded that the number of reviews was not adequate, 97.9% said that management or a technical expert did not have time to do additional reviews.
 - In addition, 87.4% of respondents reported 1-2 complaints from the public each week about the accuracy or timeliness of their work.
- 5) **Field Office Telephone Calls**
- The Field handled 58 million calls in FY 2009, 4 million more calls than in FY 2008.
 - SSA studies by the Office of Quality Performance state that Field Office telephone busy rates were about 58% in FY 2009, which is an increase of 3% over the prior fiscal year. Many offices must direct staff to handle walk-in traffic to reduce waiting times and, as a result, are left with insufficient staff to answer telephone calls.
 - In the February 2010 NCSSMA Survey of Management, 68% of respondents said that to a moderate or very large degree the increased number of visitors is due to the inability to answer phones and 65% said they provide prompt phone service 50% or less of the time.
 - Also, 98.1% of survey respondents said they receive at least 1-2 complaints per week about poor Field Office phone service with 72.8% of the respondents stating they receive 3-4 or more complaints about poor Field Office phone service.
- 6) **Additional SSI Redeterminations/Limited Issue Cases**
- In FY 2010, Field Offices will work about 1.202 million more SSI redeterminations (including Limited Issues) than FY 2008. The FY 2011 budget request proposes to clear the same number of cases (2,422,000) as FY 2010. This is approximately a 100% increase for FY 2010 and FY 2011 over FY 2008.
 - Additionally, the Martinez Court Case (Fugitive Felons) requires additional Field Office resources as these redeterminations are more time consuming than regular redeterminations because in many instances they must be developed back further.
 - Technicians processing redeterminations are working at a very high rate of production and concerns exist about insufficient time to review the cases adequately for accuracy.
- 7) **SSN Application Process**
- The task time for Field Office/Enumeration Center processing of a Social Security card has increased with the implementation of new procedures related to the paperless processing of claims. Representatives must ask additional questions and read attestation scripts not required during the prior process.
 - Anecdotal information from Field Offices indicates that it takes a minimum of two minutes longer per interview for Social Security card applications processed.
- 8) **Medical Continuing Disability Reviews (CDRs)**
- In both FY 2009 and FY 2010, SSA is scheduled to process 329,000 medical CDRs, which is an increase of 104,000 over FY 2008. (Note: SSA actually processed 316,960 CDRs for FY 2009.)
 - In FY 2011, the budget request proposes to increase that amount by 31,000 more medical CDRs. Currently there is a backlog of 1.5 million medical CDRs awaiting processing and Field Offices need additional resources to process the front and back end of these cases.

It is important to note that in FY 2011 SSA will need a minimum administrative budget increase of \$770 million just to cover inflationary costs, including maintaining workyears initially funded by the American Recovery and Reinvestment Act of 2009 (ARRA), rent, guards, postage, periodic step increases, career ladder promotions, increased health benefit costs, new employees hired under the Federal Employees Retirement Systems (FERS), and annual pay increases.

We greatly appreciate the increased funding that SSA received for Fiscal Year 2009 and Fiscal Year 2010. This includes the \$1 billion SSA received from ARRA. About half of that funding was directed to reducing the backlogs in SSA. Had SSA not received this funding the service we provide in SSA would be much worse and the disability backlogs would be unconscionable.

Once again, we are very supportive of the President's FY 2011 budget request for the Social Security Administration (SSA). The total SSA budget request is \$12.528 billion, which includes \$12.378 billion in administrative funding through the Limitation on Administrative Expenses (LAE) account. We respectfully request that you provide at least the full President's budget request for SSA in FY 2011.

As you know, the Commissioner of Social Security did submit an independent budget for SSA for FY 2011. The proposed amount for the Limitation on Administrative Expenses (LAE) account was \$13.1 billion. This is \$721 million more than the level proposed by the President. This budget would have increased SSA staffing by an additional 3,144 positions or 3,758 positions above Fiscal Year 2010. The President's proposed budget for Fiscal Year 2011 increases SSA's staffing by only 614 positions over Fiscal Year 2010. (These increases do not include the DDSs.)

The Commissioner's proposed budget would have eliminated most of the backlogs in SSA, improved Field Office telephone service, addressed program integrity and quality concerns, and resulted in significant improvements in service to the American public.

We recognize there is no silver bullet to providing the necessary resources for SSA. We will need continued funding support above current levels to keep up with our growing workloads, reduce existing backlogs, and meet rising customer service expectations.

Our community based staffs are very committed to serving the American public, but we must have the tools and resources to do so. We sincerely appreciate your ongoing support to provide adequate funding for the Social Security Administration. We remain confident that this increased investment in SSA will benefit our entire nation.

On behalf of the members of NCSSMA I thank you again for the opportunity to submit this written statement. NCSSMA members are not only dedicated SSA employees, but they are also personally committed to the mission of the agency and to providing the best service possible to the American public. We respectfully ask that you consider our comments and would appreciate any assistance you can provide in ensuring that the American public receives the necessary service that they deserve from the Social Security Administration.



National Council of State Directors of Adult Education
Joanie Rethlake, Chair

Testimony of

Joanie Rethlake, Chair
National Council of State Directors of Adult Education

Before the

Subcommittee on Labor, Health and Human Services Education and Related Agencies

House Committee on Appropriations

Mr. Chairman, thank you for the opportunity to submit testimony regarding the need for additional appropriations for adult education programs.

Adult education programs serve a large number of our nation's at-risk citizens, from those who are unemployed to immigrants who lack the literacy skills needed to succeed in their new home country.

At the present time our country is heavily investing in efforts to put Americans back to work. For many of our nation's unemployed, their jobs have disappeared, only to be replaced by new jobs with requirements they cannot meet because they have low literacy skills and lack a high school diploma.

To meet the needs of these individuals, adult education programs across the nation are partnering with programs under Title I of the Workforce Investment Act to develop career pathways that integrate adult education and occupational training programs. In addition, there are programs focused on transitioning participants from adult education programs to postsecondary education.

But current funding levels, coupled with funding from the state and local level, prevent us from serving more than 2.3 million individuals a year. A 2010 survey demonstrates that there are **waiting lists in every state**. According to the National Assessment of Adult Literacy, there are approximately 93 million individuals who lack the literacy skills to reach their full potential. Thirty million individuals are at the lowest level of literacy and cannot perform basic tasks such as reading a bus schedule.

With the wide gap between the number of Americans who are in need of improved literacy/education skills and the number that can be served by the current system, we strongly encourage you to increase funding for adult education state grant programs to \$750 million which would enable us to at least erase the waiting list.

Mr. Chairman, adult education programs help put Americans back to work, provide new immigrants with English language skills, assist in transitioning individuals to higher education, and provide parents with the skills they need to help their children succeed in school.

Adult education programs provide a wide range of services to many individuals but are currently limited in the number of individuals we can serve because of limited funding. While we understand the budget is tight, we believe increased funding for adult education will provide a strong return on your investment in our programs while we serve undereducated adults.

Thank you again for the opportunity to submit testimony regarding funding for adult education programs.

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April 6, 2010

The Honorable David Obey
Chairman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
U.S. House of Representatives
H-218 Capitol
Washington, DC 20515

The Honorable Todd Tiaht
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
U.S. House of Representatives
2112 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Obey and Ranking Member Tiaht:

Chairman Obey, Ranking Member Tiaht, and Members of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, I am Julie Block, Chief Executive Officer of the National Eczema Association.

As Members of Congress who strongly value the role of the National Institutes of Health (NIH), I am writing first to express to you my deep gratitude for your past support. The NIH is our nation's preeminent medical research institution and represents our best hope for finding cures, improving treatments, and gaining a better understanding of the diseases and conditions that affect millions of Americans. On behalf of the National Eczema Association, I respectfully request your continued support for NIH funding.

I would also like to thank you for inviting us to submit testimony on our own behalf. The National Eczema Association (NEA) is a 501(c)(3) non-profit organization that receives no federal grants or sub grants, nor do we receive federal contracts or subcontracts. Our mission is to help improve the health and quality of life of persons living with eczema/atopic dermatitis, including those who have the disease and their loved ones. This is a family disease. Through programs focused on advocacy, education, and research, we involve both public and private sectors in addressing these needs. In these current times, there is much the public does not know or understand about how devastating this disease can be.

There are many types of eczemas, with atopic dermatitis (AD) recognized as the most severe and chronic. Atopic dermatitis is a genetic skin disease that affects over 30 million people in the United States; 10 percent of the American populations have some form of atopic dermatitis.

Atopic dermatitis falls into a category of disease called atopy, which includes asthma and hay fever. The three together are known as the "Atopic Triad." Atopic dermatitis almost always begins in childhood, usually during infancy. However, it is important to remember that atopic dermatitis is not just a childhood disease, as is commonly believed. For most people afflicted with the disease it becomes a lifelong sentence. The skin becomes dry, scaly, red and *intensely* itchy. It cracks, bleeds, weeps, and often gets infected.

For many patients with eczema, one of the worst consequences of the disease is the isolation and withdrawal from other people and community. Patients are often treated as if they were lepers even though atopic dermatitis is not contagious. Some patients choose not to have children, fearful of passing on a life of suffering to yet another generation. Some patients feel this choice so strongly they submit to voluntary sterilization in young adulthood. Atopic dermatitis is an extremely isolating disease, regardless of whether that isolation stems from internal or external factors, and many severe atopics do not leave their homes.

Others, like the young heroine of the story I'm about to relate, somehow find within themselves the courage to keep going, to keep fighting, to keep believing there is a place for them in the larger community. I hope her story not only inspires you, but inspires you to action.

This is Angeline's story. Angeline is an adult atopic, having eczema since birth. Her nickname in school was "Spot" – she would hide in the bathrooms during recess and lunchtime and *scratch*. She would try with all her might not to scratch during class, not to flake skin over her desk, not to crack and bleed. Constant, intolerable, itching has led to lifelong use of steroid treatments, both orally and topically, to assuage the itching and "treat" the eczema wounds. The constant itching, skin flaking off in sheets, dead, dry skin, and oozing abhorrent looking skin are just part of everyday life for Angeline.

Her eczema has resulted in severe infections, and this physical trauma is accompanied by a level of psychic trauma few of us ever have to confront. She has had too many days when she can literally not get out of bed - the skin gets so bad that it eventually becomes a huge task to even move her legs and arm joints. On top of all that, her skin looks absolutely gruesome.

Angeline has shed many tears, and at times wondered how she would go on. The years of bandaged hands to stop the scratching, steroid withdrawal, bank accounts spent on creams and miracle cures, vitamins and doctors appointments. When will it end? Some days Angeline is not at all available to "face the world".

And people will tell you eczema is just a rash!

As Angeline's story suggests, doctors, researchers, and scientists consistently underestimate the emotional consequences of this disease, its treatments, and its complications. The general public understands it even less. Before we can offer alternatives that will truly improve the quality of life for eczema sufferers, we must understand the disease mechanism and how it works. Committed physicians and ongoing research gives us all hope.

The National Eczema Association is dedicated to raising awareness of these issues. The Association publishes a quarterly newsletter called *The Advocate*, oversees a volunteer Support Network program, distributes educational materials to patients and medical professionals, and conducts an annual Patient and Family Conference. As vocal advocates for atopic patients and their families, our staff attends several professional meetings each year, and educates governmental officials at local, state and national levels to provide input to the budget, research, and policy decisions about atopic dermatitis/eczema patients. In past years, the National Eczema Association educated public officials during the government's smallpox vaccination campaign regarding the life-and-death consequences to atopic patients. We have been on Capitol Hill for NIAMS day many years in a row as a member of the National Institutes of Arthritis and Musculoskeletal and Skin Diseases Coalition to educate legislators on our disease.

The National Eczema Association (NEA) can boast many exciting accomplishments, including over \$400,000 spent on eczema research since the inception of its research program in 2004. One of the NEA funded grants to Dr. Gil Yosipovitch, MD of Wake Forest University has resulted in a major NIH grant to continue his work on itch. We anticipate yet another NIH award for NEA funded research to continue exciting work on prevention of atopic dermatitis in high risk infants.

The NIH and the research it supports are critical to the advancement of improved atopic dermatitis/eczema treatment and eventual cure. As part of the Coalition of Skin Disease, we believe that when a cure is found for any of these skin diseases, there is a good chance it will improve our ability to find a cure for other diseases. The recent boost in NIH funding in 2009 and 2010 was a very important step toward regaining the lost potential of the last several years.

As you work to finalize the Fiscal Year 2011 appropriations, on behalf of the National Eczema Association, I respectfully request a funding increase of at least 7 percent for the National Institutes of Health (NIH) compared to the Fiscal Year 2010 baseline level.

Help us give eczema patients and their families hope for the pleasure of everyday life, and being good in the skin their in!

And again, thank you for your past support of biomedical research funding.

**TESTIMONY
OF
THE NATIONAL ENERGY ASSISTANCE DIRECTORS' ASSOCIATION
BEFORE THE SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,
AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE
FY 2011 APPROPRIATIONS REQUEST FOR
THE LOW INCOME HOME ENERGY ASSISTANCE PROGRAM**

April 15, 2010

**National Energy Assistance Directors' Association
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The members of the National Energy Assistance Directors' Association (NEADA) would like to first take this opportunity to thank the members of the Subcommittee for its continued program support. For FY 2010, funding was maintained at \$5.1 billion, the fully authorized funding level for the program. This is the second year that the Committee has made this funding level available to the states to help poor families pay for home energy during these difficult economic times.

The number of households receiving heating assistance reached record levels for a second year, increasing from 7.7 million to 8.8 million households. An additional 583,000 are expected to receive cooling assistance this year as well. Lower energy prices allowed the states to maintain the program's purchasing power at about 45 percent of the cost of home heating.

For FY 2011 we are requesting that the Subcommittee maintain full funding for LIHEAP in order to maintain services for the 8.8 million households that received heating assistance, the 583,000 expected to receive cooling assistance in FY 2010, and provide \$600 million in emergency funding authority. In addition, to these funding requests, we are concerned that states will be hampered in their ability to administer their programs efficiently due to the lack of advanced funding. The lack of a final program appropriation prior to the beginning of the fiscal year creates significant administrative problems for states in setting their program eligibility guidelines. In order to address this concern, we are requesting advance appropriations of \$5.1 billion for FY 2012 and \$600 million in emergency contingency fund authority.

The President's 2011 Budget for LIHEAP would reduce funding to \$3.2 billion, assuming all emergency funds were released. The Administration's proposal for an automatic adjustment or "trigger" in the event of rising prices for home energy and higher caseloads for the Supplemental Nutrition Assistance Program offers the promise of providing additional stability for protecting the purchasing power of energy assistance appropriations and purports to make up the difference between the \$5.1 billion received this year and the \$3.2 billion requested.

The members of NEADA are concerned, however, that the trigger provision would result in payment delays and increase the administrative burden on the program. Instead we are recommending that this type of provision, including an adjustment for extreme weather conditions should be considered as a complement to a fully funded program at \$5.1 billion and could be used to replace or complement the program's emergency contingency fund authority.

The Impact of the FY 2010 Appropriation

Record levels for households receiving energy assistance are being reported by states across all parts of the country. The number of households receiving heating assistance increased by more than 20 percent in the following 16 states:

- 25% or greater: Mississippi (68 percent), Washington (42%), Michigan (38%), New Jersey (31%), West Virginia (28%), Colorado (26%) Kansas, New Hampshire and Wisconsin (25%)
- 20% to 24%: Montana (21%), California, Oregon, South Carolina, South Dakota, Texas and Rhode Island (20%).

Energy Prices Remain High

The recent decline in natural gas, propane and electricity prices has helped to slow the rate of increase in home energy prices. However, prices remain high and for many low income Americans – unaffordable. As shown in the following table, average home heating costs have increased by almost 31 percent from \$793 to \$1,038 between the winter heating seasons of 2004-05 and 2008-09 and then declined by 5.8 percent during the recently completed winter heating season of 2009-10 for a net increase of 23.3 percent during this period.

LIHEAP: Winter Heating Program Purchasing Power

Est. Average % of Home Heating Purchased with LIHEAP (FY 03- FY 10)

| Fiscal Year | Heating Oil | Natural Gas | Propane | Electricity | All Fuels |
|-------------|-------------|-------------|---------|-------------|-----------|
| 2005 | 27.2% | 43.4% | 29.0% | 44.3% | 40.3% |
| 2006 | 30.2% | 45.2% | 33.4% | 54.1% | 44.9% |
| 2007 | 20.1% | 35.7% | 21.6% | 35.1% | 32.3% |
| 2008 | 16.9% | 38.4% | 19.6% | 38.3% | 33.3% |
| 2009 | 26.5% | 55.5% | 25.3% | 51.8% | 47.6% |
| 2010 | 23.8% | 58.1% | 25.6% | 47.7% | 46.7% |

Est. Home Heating Costs (2004-05 to 2009-10)

| Winter Heating Season | Heating Oil | Natural Gas | Propane | Electricity | All Fuels |
|-----------------------|-------------|-------------|---------|-------------|-----------|
| 2004-05 | \$1,176 | \$738 | \$1,103 | \$722 | \$793 |
| 2005-06 | \$1,409 | \$943 | \$1,277 | \$787 | \$948 |
| 2006-07 | \$1,445 | \$815 | \$1,347 | \$828 | \$900 |
| 2007-08 | \$1,953 | \$858 | \$1,681 | \$861 | \$990 |
| 2008-09 | \$1,864 | \$889 | \$1,950 | \$953 | \$1,038 |
| 2009-10 | \$1,921 | \$786 | \$1,785 | \$957 | \$978 |
| % Change 2005-08 | 58.5% | 20.5% | 76.8% | 32.0% | 30.9% |
| % Change 2005-09 | 63.4% | 6.5% | 61.8% | 32.5% | 23.3% |
| % Change 2009-10 | 3.1% | -11.6% | -8.5% | 0.4% | -5.8% |

Est. Households Served & Average Grant (FY 03- FY 10)

| Fiscal Year | Appropriation (in thousands) | Households (in thousands) | Average Grant |
|-------------|------------------------------|---------------------------|---------------|
| 2005 | \$2,186,000 | 5,083 | \$320 |
| 2006 | \$3,162,000 | 5,521 | \$426 |
| 2007 | \$2,186,000 | 5,592 | \$291 |
| 2008 | \$2,570,000 | 5,798 | \$330 |
| 2009 | \$5,100,000 | 7,684 | \$494 |
| 2010 | \$5,100,000 | 8,832 | \$456 |

- Source: Energy Information Administration, Short Term Energy Outlook, March 2010 and State Reports

Increased LIHEAP Funding Helped Families Maintain Access to Home Energy During the Economic Recession

We recently completed the 2009 National Energy Assistance Survey (NEA). This survey documented changes in the affordability of energy bills, the need for LIHEAP, and the choices that low-income households make when faced with unaffordable energy bills. Because of continuing high energy prices and rising unemployment during the survey period, we expected an even higher percentage of families to report that they were unable to pay their home energy bills or had to make even greater sacrifices than in previous years to maintain access to home energy.

In fact, LIHEAP recipients reported that the funding was more essential this year than in the past: 93 percent of recipients reported that LIHEAP funding was very important in helping them keep the heat on in the winter and cooling in the summer up from 90 percent in 2008 and 74 percent in 2003. The additional LIHEAP funding also increased the odds that a household could work out a payment plan with their local utility. The number of households that reported this increased from 54 percent in 2008 to 61 percent in 2009.

LIHEAP benefits increased since the previous year due to the greater appropriation in FY 2009. About 21 percent received total LIHEAP benefits of more than \$750 in FY 2009, compared to 12 percent in FY 2008. The pre-LIHEAP energy burden averaged 16 percent and post-LIHEAP energy burden averaged 11 percent for these households, compared to 7 percent for all households in the U.S. and 4 percent for higher income households in the U.S.

Increased LIHEAP Funding Helped to Reduce the Impact of the Recession on Low Income Households

Without the increase in funding in FY 2009, there is no question that LIHEAP recipients would have faced even greater hardships than in previous years. Nevertheless, many of the families receiving LIHEAP struggle to pay their energy bills, and frequently have to choose between paying for home energy or food.

LIHEAP recipient households are likely to be vulnerable to temperature extremes. They are likely to have seniors, disabled members, or children in the home. More than 90 percent of LIHEAP households had at least one of these vulnerable household members. The study also showed that these households face many challenges in addition to their energy bills, including unemployment, unhealthy home conditions, and medical issues.

LIHEAP recipients reported that they faced high energy costs. Over one third of the respondents reported energy costs over \$2,000 in the past year and 35 percent said that their energy bills had increased over the previous year.

Households reported that they took several actions to make ends meet, including closing off part of the home and leaving the home for part of the day. Some of the actions taken by these households were unsafe and could lead to injury or illness, such as keeping the home at a temperature that was unsafe or unhealthy or using the kitchen stove or oven to provide heat.

Many of the LIHEAP recipients faced significant medical and health problems in the past five years, partly as a result of high energy costs. Nearly one third reported that they went without food, over 40 percent sacrificed medical care, and one quarter had someone in the home become sick because the home was too cold.

The Need for LIHEAP

Households reported enormous challenges despite the fact that they received LIHEAP. However, they reported that LIHEAP was extremely important. About 64 percent reported that they would have kept their home at unsafe or unhealthy temperatures and/or had their electricity or home heating fuel discontinued if it had not been for LIHEAP. Almost 98 percent said that LIHEAP was very or somewhat important in helping them to meet their needs. In addition, 53 percent of those who did not have their electricity or home heating fuel discontinued said that they would have if it had not been for LIHEAP.

It is clear that many of these households will continue to need LIHEAP to meet their energy and other essential needs. Almost ninety percent said that they have or plan to apply for LIHEAP in the next year.

The members of NEADA recognize the difficult budget decisions that you face as you consider funding levels for LIHEAP for FY 2011 and advance funding for FY 2012. We appreciate your interest and continued support for LIHEAP. Please feel free to call upon us if we can provide you with additional information.

National Energy Assistance Directors' Association
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**National Federation of Community Broadcasters Testimony to the
Senate and House Appropriations Subcommittees on Labor, Health and Human Services,
Education and Related Agencies Regarding the Fiscal Year 2013 Appropriations
for the Corporation for Public Broadcasting
Encompassed in the Fiscal Year 2011 Appropriation Legislation**

**Testimony of Maxie C. Jackson, III
President and CEO
April 12, 2010**

Thank you for the opportunity to submit testimony to this Subcommittee regarding the appropriation for the Corporation for Public Broadcasting (CPB). As the President and CEO of the National Federation of Community Broadcasters (NFCB), I speak on behalf of 250 community radio stations and related individuals and organizations across the country. Nearly half our members are rural stations and half are controlled by people of color. In addition, our members include many Low Power FM stations that are putting new local voices on the airwaves. NFCB is the sole national organization representing this group of stations which provide independent, local service in the smallest communities of this country as well as the largest metropolitan areas. In summary, in this testimony, NFCB:

- Thanks the Committee for its role in providing \$25 million station fiscal stabilization in light of the difficult economy in last year's appropriation;
- Requests \$604 million in funding for CPB for FY 2013 and requests that advance funding for CPB is maintained to preserve journalistic integrity and facilitate planning and local fundraising by public broadcasters;
- Supports CPB activities in facilitating programming and services to the radio "minority consortia" dedicated to Native American, Latino and African-American radio stations;
- Requests \$59.5 million in FY 2011 for conversion of public radio and television to digital technology;
- Supports CPB's funding for rural stations and assistance with new technologies and requests report language regarding rural and minority stations in this regard
- Supports CPB programs focused on ensuring public radio is able to fulfill its important mission of public safety during emergencies; and
- Supports CPB's role as a convener that can address questions and important future trends across all public media.

Community radio fully supports the forward funding appropriation of \$604 million in federal funding for the Corporation for Public Broadcasting in Fiscal Year 2013. Money allocated to the Corporation for Public Broadcasting assists NFCB member stations throughout the country through community service grants. Community service grants are the core way that CPB uses to support radio stations—particularly targeted to stations offering the first public radio service to a community in a rural area, or to stations serving particular demographic constituencies. CPB's focus on these areas is critical to ensuring that public radio does not focus solely on higher-income audiences, but serves every American no matter their background or

their location. These targeted stations provide critical, life-saving information to their listeners and are often in communities with very small populations and limited economic bases, thus the community is unable to financially support the station without federal funds. For example, these stations offer programming in languages other than English or Spanish, they can offer emergency information targeted for a particular geographic area, and can offer in-depth programming on public health issues.

In larger towns and cities, sustaining grants from CPB enable Community Radio stations to provide a reliable source of noncommercial programming about the communities themselves. Local programming is an increasingly rare commodity in a nation that is dominated by national program services and concentrated ownership of the media. CPB funding allows an alternative to exist in these larger markets. And with large newspaper shedding journalists, local community radio may be one of the only outlets able to pick up the slack in coverage of local political matters.

For over 30 years, CPB appropriations have been enacted two years in advance. This insulation has allowed public broadcasting to grow into a respected, independent, national resource that leverages its federal support with significant local funds. Knowing what funding will be available in advance has allowed local stations to plan for programming and community service and to explore additional non-governmental support to augment the federal funds. Most importantly, the insulation that advance funding provides is of critical importance in eliminating both the risk of and the appearance of undue interference with and control of public broadcasting.

Community radio supports CPB activities in facilitating programming to Native American, Latino and African-American radio stations. CPB has played a critical role in providing support and assistance to radio stations serving communities of color, particularly communities that could be better served by noncommercial radio. While CPB has long supported television programming focused on underserved communities, its programs for radio are newer and are very welcome. Given the importance and accessibility of radio in many underserved communities, NFCB urges the Subcommittee to endorse the long-term viability of these radio minority consortia.

Specifically, with important support from CPB, Native Public Media (NPM) has burst on to the scene to ensure that Native Americans have access to noncommercial broadcast and new technologies alike. NPM has worked in the last few years to facilitate applications for noncommercial radio stations by almost 40 applicants from tribal and native entities, bringing many of these service areas within the reach of a public radio signal for the first time. NPM has undertaken research to identify the spectrum allocations currently serving Indian Country in order to target better service in the future, releasing a report called *The New Media, Technology and Internet Use in Indian Country: Quantitative and Qualitative Analyses*, which included a usage survey and case study that contains the first valid and credible data on Internet use among Native Americans. In addition, NPM was able to play a critical role in ensuring that tribal entities have the ability to obtain new radio stations in the future by successfully demonstrating to the FCC the need and legal justification for a tribal priority in radio.

In addition, in the last year the newest minority consortium has been started—the Latino Public Radio Consortium. The Latino Public Radio Consortium is an organization that represents and supports thirty-three public radio stations. It recognizes that Latinos are underrepresented in the nation's public broadcasting institutions, decision-making structures, that there is little programming in English or in Spanish produced by Latinos or with a Latino focus

and, as a consequence, Hispanics are vastly underrepresented among public radio's news and public affairs audiences.¹ To illustrate, a study by Station Resource Group's *Grow the Audience* project showed that, for public radio to acquire a representative share of the college-educated market for Latinos, it would need to triple its audience.²

During this funding year the Consortium has established the communications and governance structure to enable the Hispanic stations to support each other and to develop additional resources. An important new project that is indicative of future work is the development of *Historias*, a partnership with Story Corps, a national oral history project of the Library of Congress and public radio. Through this collaboration, Story Corps *Historias* will gather and record 900 individual interviews with Latinos around the country.

This year CPB is funding new services for African American public radio stations designed to improve and increase public media's service to the American public. NFCB believes that this project, like the other consortia, is vital to ensure that all Americans benefit from public funds and the breadth and depth of public radio. In addition to the minority consortia, CPB supports Satélite Radio Bilingüe which provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues of particular interest to the Latino population in Spanish and English. CPB also supports Native Voice One (NV1), which is distributing politically and culturally relevant programming to Native American stations.

Community radio supports \$59.5 million in FY 2011 for the conversion to digital technology. While public television's digital conversion needs were mandated by the FCC, public radio is converting to digital to provide more public service and to keep up with commercial radio. The Federal Communications Commission has approved a standard for digital radio transmission that will allow multicasting. This development of second and third audio channels will potentially double or triple the service that public radio can provide listeners, particularly in unserved and underserved communities. In addition, public radio is in great need of CPB's leadership and resources to transition to new media platforms, in particular through such projects as the American Archive, which will make existing programming accessible to all and on all platforms.

Community radio supports CPB's funding for rural stations and assistance with new technologies. For the past few years, CPB has increased support to rural stations and committed resources to help public radio take advantage of new technologies such as the Internet, satellite radio and digital broadcasting. We support these new technologies so that we can better serve the American people, but want to ensure that smaller stations with more limited resources are not left behind in this technological transition. We ask that the Subcommittee include language in the appropriation that will ensure that funds are available to help the entire public radio system, particularly rural and minority stations, utilize new technology.

A good example of CPB's role is the Public Media Innovation grant CPB gave KAXE, one of NFCB's rural members, a chance to experiment with the concept of becoming "a web operation that owned a radio station." PMI described this project as one of the most visionary proposals they funded. As part of the grant, KAXE began the development of Northern Community Internet, which would provide hyper-local news content to more than a dozen

¹ Latino Public Radio Consortium, Brown Paper, p.1 available at <http://www.latinopublicradioconsortium.org/index.php?s=41>.

² Station Resource Group, *Grow the Audience, Listening by Black and Hispanic College Graduates* (2008) at p. 17, available at <http://www.srg.org/GTA/GTA%20Black%20Hispanic%20Report.pdf>.

communities in northern Minnesota. Through this project, KAXE learned many important things about how to create content that is relevant and accessible across a web site, radio station, and social media. The journalists involved continue to be very interested in the project, even though the current pilot is over.

Community radio supports CPB programs focused on ensuring public radio is able to fulfill its important mission of public safety during emergencies. CPB funding has supported an important new project led by NFCB called Station Action for Emergency Readiness (SAFER). NFCB, in partnership with NPR and with support from CPB, has developed a step-by-step manual that stations can use to develop and/or supplement their own emergency readiness plans; a set of digital tools that stations can embed in their own websites to keep community members informed; and links to national and local resources that can supplement station's coverage. This project was inspired by the experience of NFCB member WWOZ in New Orleans as a result of Katrina and was furthered by the work of NFCB member KWMR in Point Reyes Station, CA. KWMR is small and local community and provided absolutely critical life-saving information to its community during terrible floods of 2004-2005.

Community radio supports CPB's role as a convener that can address questions and important future trends across all public media. CPB plays an extremely important role in the public and Community Radio system: it convenes discussions on critical issues facing us as a system. They support research so that we have a better understanding of how we are serving listeners. And, they provide funding for programming, new ventures, expansion to new audiences, and projects that improve the efficiency of the system. This is particularly important at a time when there are so many changes in the radio and media environment with media consolidation and new distribution technologies.

Thank you for your consideration of our testimony. If the Subcommittee has any questions or wishes to follow up on any of the points expressed above, please contact:

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The NFCB is a grassroots organization founded in 1975 established by--and still supported by--our member stations. Large and small, rural and urban, NFCB member stations are distinguished by their commitment to local programming, community participation and community support. NFCB's 250 members come from across the United States, from Alaska to Florida, from every major market to the smallest Native American reservation. While urban member stations provide alternative programming to communities that include New York, Los Angeles, San Francisco, Chicago, and other major markets, rural members are often the sole source of local and national daily news and information in their communities. NFCB's membership reflects the true diversity of the American population: 41% of members serve rural communities, and 46% are radio services controlled by people of color.

On Community Radio stations' airwaves examples of localism abound: on KWSO in Warm Springs, Oregon, you will hear morning drive programs in the Native language of that community; throughout the California farming areas in the central valley, Radio Bilingüe programs six stations targeting low-income farm workers; in Chevak, Alaska, on KCUK you will hear the local weather reports and public service announcements in Cup'ik/Yup'ik Eskimo; in Dunmore, West Virginia, you will hear coverage of the local school board and county commission meetings; KABR in Alamo, New Mexico serves its small isolated Native American population with programming almost exclusively in Navajo; and on WWOZ you can hear the sounds and culture of New Orleans throughout the day and night.

Fiscal Year 2011 Appropriations Request

**House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education, and
Related Agencies**

April 12, 2010

Testimony for the Printed Record

**Adrienne Breidenstine
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National Health Care for the Homeless Council
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The National Health Care for the Homeless Council respectfully asks the House Committee on Appropriations to strengthen and expand the nation's health centers by appropriating the \$2.4 billion for the Consolidated Health Centers Program in Fiscal Year 2011, as included in the Administration's budget proposal.

The National Health Care for the Homeless Council is a membership organization engaged in education and advocacy to improve health care for homeless persons and all Americans. We represent 111 organizational members, including 100 Health Care for the Homeless projects, and over 700 individuals who provide care to people experiencing homelessness throughout the country.

Homelessness & Health: Poverty, lack of affordable housing, and the lack of comprehensive health insurance are among the underlying structural causes of homelessness. For those struggling to pay for housing and other basic needs, the onset of a serious illness or disability easily can result in homelessness following the depletion of financial resources. The experience of homelessness causes poor health, and poor health is exacerbated by restricted access to appropriate health care – which only prolongs homelessness. Additional barriers to health care access include lack of transportation, inflexible clinic hours, complex requirements to qualify for public health insurance, and mandatory unaffordable co-payments for various services.

Mainstream health care safety net providers often fail to meet the needs of homeless people. In the absence of universal health care, the Federal government supports a separate health care system for low-income and uninsured people. Community Health Centers and publicly funded mental health and addictions programs form the core of this health care safety net. Unfortunately, limited resources, lack of experience with this population, and insufficient linkages to a full range of health and supportive services

seriously restrict the ability of mainstream providers to meet the unique needs of people experiencing homelessness.

The Federal Health Care for the Homeless Program—administered by the Health Resources and Services Administration (HRSA)—currently supports 207 HCH projects in all 50 states, the District of Columbia, and Puerto Rico. Congress established Health Care for the Homeless (HCH) in 1987 to provide targeted services for people experiencing homelessness, including primary and behavioral health care along with social services, as well as intensive outreach and case management to link clients with appropriate resources. Approximately 70% of those served by HCH projects lack comprehensive health insurance. The HCH program has been reauthorized three times, most recently in 2008 with passage of the *Health Care Safety Net Act*. HCH projects served over 1 million patients in 2009 – a sizable number, but far below the estimated 4 million Americans who annually experience homelessness. Authorizing language designates 8.7% of the total Health Center appropriation to support the HCH program.

Community Health Centers: Over the past several years, the expansion of community health centers has received bipartisan support from Members of Congress, to include through the American Recovery and Reinvestment Act of 2009 (ARRA). Federally-Qualified Health Centers (FQHCs) consistently have proven their effectiveness in delivering comprehensive medical care to underserved populations. Though health centers currently serve more than 16 million people annually, at least 56 million Americans—both insured and uninsured—face inadequate access to primary care due to a shortage of physicians and other providers. Without sufficient access to care, the health problems of the insured and underinsured are exacerbated, resulting in costly treatment, medical complications, and even premature death.

Investments in Community Health Centers contained the *Patient Protection and Affordable Care Act* will also be a significant tool that will help clinics grow to meet the needs of patients seeking primary care, especially as the Medicaid expansion provisions are enacted in 2014. This Medicaid expansion will be a greatly needed improvement for our homeless patients, since most are currently ineligible for coverage.

Within the current economic context, a massive unmet need remains for health center resources despite years of incremental expansion through the Health Center Growth Initiative. The deteriorating economy leaves more Americans unemployed, at risk of homelessness, and in need of health services. According to the Department of Labor, the unemployment rate was 9.7% in March 2010. Given the prevalence of employer-sponsored health coverage, high unemployment leaves many Americans without health coverage, thus creating a greater need for safety net services provided by community health centers.

Fiscal Year 2011 Appropriations: In recognition of the growing need for primary health care services, the House Committee on Appropriations along with other Members of Congress has been supportive of strengthening and expanding community health centers. In the President's Fiscal Year 2011 Budget Proposal, the Community Health

Center program receives \$2.4 billion – \$290 million above the FY 2010 appropriation. This includes a total of \$209 million (8.7%) for the HCH program.

To continue strengthening the nation's health center infrastructure, we encourage the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Other Related Agencies to appropriate the \$2.4 billion for the Community Health Center program (including \$209 million for the HCH program), as contained in the Administration's FY2011 budget proposal.

The National Council applauds Congress for its strong support of community health centers. We thank Chairman Obey and the House Committee on Appropriations Subcommittee on Labor, Health and Human Service, Education, and Other Related Agencies for your consideration of this testimony.

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Public Witness Testimony for the Record
Submitted to
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
April 16, 2010

Chairman Obey and Committee Members, I am Elena Rios, President and CEO of the National Hispanic Medical Association, a nonprofit association representing over 45,000 Hispanic physicians. The mission of the NHMA is to improve the health of the Hispanic population through physician leadership and advocacy.

This testimony is to urge your support for President Obama's FY2011 Budget requests for the Department of Health and Human Services and related agencies with his vision to provide secure and affordable health care for all Americans.

The members of NHMA are champions for their communities who, in general, are underserved with low income and educational attainment and who face severe lack of health care, mental health and preventive health care services. Our communities need a transformation to become healthier communities with the support for health promotion in the homes, worksites, schools, buildings and the environment. Our communities need a transformation for health care services and research and communications to be linked to individuals and families in their communities and not merely through health care delivery.

In order to advance this transformation, health care reform legislation, demands new vision and services that are responsive to the Hispanic population, now the largest ethnic group in the nation and growing to be one out of four Americans by 2042. The President's budget can build our communities of the future.

We strongly believe we need the President's Budget to address the following critical areas:

1. Community health education and communications programs with collaborative partnership between community health centers, public health departments, medical groups and community based organizations that increase awareness of preventive services as well as treatment services and public health education. NHMA strongly believes that physicians need to be utilized as spokespersons and community leaders.
2. Community-based research from NIH, AHRQ and CDC that links the academic researchers with community based organizations and community based researchers with HHS directly. We believe that our regional communities need to have documentation

about the needs and innovations required to improve HHS research of the future. We also recommend that the comparative effective research look at the Hispanic population.

3. Expand the primary care physicians and other providers with an emphasis on training in the communities so that future health care workforce is better prepared to care for Hispanics.
4. Expand the Health Career Opportunity Program and the Centers of Excellence of Title VII to include cultural competence training and leadership in public health training programs so that the future health care workforce is more diverse. One example that we have called for in the past is to build regional Hispanic Centers of Excellence that can demonstrate innovation in training the workforce to better care for the growing Hispanic population.
5. We especially support the development of the national workforce strategy to include diversity as a mandate and to support the effort to promote mentorship for Hispanic physicians to become prepared for public service at the U.S. Department of Health and Human Services, which remains a Federal agency with one of the poorest records of inclusion of Hispanic employees at all levels. One example would be to develop the public health workforce at the CDC with a targeted Hispanic physician workforce initiative to increase the
6. Expand the programs to adopt and develop a national Health IT program, especially for medical groups, clinics and hospitals that care for the safety net populations, to improve the efficiency of care, decrease fraud and waste and costs.
7. Decrease health care disparities and health disparities among Hispanics and other ethnic minority groups by focusing support for prevention and health care for patients with chronic diseases, especially diabetes, obesity, heart disease, cancer, HIV/AIDS that have tremendous impact on the ethnic and minority populations, limiting their quality of life and prompting premature death. We support a collaborative approach at the local level to target these programs with evaluation and sharing of results.
8. Expand health care through targeted lifespan programs – maternal and child care, adolescent care, aging programs, Medicare to decrease health disparities.

In summary, the National Hispanic Medical Association supports the President's FY2011 Budget and calls for the approval of these programs that will improve the health of all Americans.

**Testimony Regarding Fiscal Year 2011 Appropriations for
Title VIII Nursing Workforce Development Programs
April 15, 2010**

**National League
for Nursing**

Submitted by: National League for Nursing
To: Subcommittee on Labor, Health & Human Services, Education, and Related Agencies,
Committee on Appropriations, U.S. House of Representatives
Agency Addressed: Health Resources and Services Administration

The National League for Nursing (NLN) is the premiere organization dedicated to excellence in nursing education and in preparing the nursing workforce to meet the needs of our diverse populations in an ever-changing health care environment. With leaders in nursing education and nurse faculty across all types of nursing programs in the United States – doctorate, master's, baccalaureate, associate degree, diploma, and licensed practical – the NLN has more than 1,200 nursing school and health care agency members, 31,000 individual members, and 23 regional constituent leagues.

The NLN urges the subcommittee to fund the Title VIII Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) at \$267.3 million in FY 2011, a 10% increase over current spending. The NLN recommends that the requested increase be directed to the Title VIII programs that have not kept pace with inflation since FY 2005: Advanced Education Nursing, Nursing Workforce Diversity, Nurse Education, Practice and Retention, and Comprehensive Geriatric Education. These programs, which help expand nursing school capacity and increase patient access to care, would benefit were the requested 10 percent increase distributed in proportion to their FY 2010 funding levels.

Nursing education, fundamental to the delivery of quality, cost-effective health care, has received emergency funding via the *American Recovery and Reinvestment Act* (P.L. 111-5), and an increase to \$243.872 million for the nursing Title VIII programs in the *FY 2010 Consolidated Appropriations Act* (P.L. 111-117). The NLN applauds the subcommittee's efforts and notes that while the passage of the health reform bills (P.L. 111-148 and P.L. 111-152) foresees a change in the funding picture, investments still fall short of the health care reality facing our nation – health inequities remain. The NLN is troubled that the nation's health demands are intensifying, and that absent consistent emphasis on building infrastructure, boosts to Title VIII will not fulfill the expectation of paying down on asset investments in the front-line that generates quality health outcomes, the nurse workforce.

THE NURSE PIPELINE AND EDUCATION CAPACITY

According to the U.S. Bureau of Labor Statistics (BLS), the registered nurse (RNs) workforce will grow by 22 percent from 2008 to 2018, resulting in 581,500 new jobs.¹ This growth will be much

¹ Bureau of Labor Statistics, U.S. Department of Labor. *Occupational Outlook Handbook, 2010-11 Edition*, Registered Nurses. On the Internet at: <http://www.bls.gov/oco/ocos083.htm> (Accessed April 2, 2010).

faster than the average for all occupations. The April 2, 2010 BLS *Employment Situation Summary – March 2010* likewise reinforces the strength of the nursing workforce to the nation's job growth.² The nation's overall unemployment rate held at 9.7 percent for March 2010, but the employment in health care continued to increase in March with the addition of 26,800 jobs in ambulatory health care services, hospitals, and nursing and residential care facilities. The BLS shows nursing as the predominant occupation in the health care industry, and notes that health care is a critically important industrial complex in the nation that grew steadily even during the depths of the recession, adding 588,000 jobs since the start of the downturn over two years ago.

While the recession has resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses, including in their own states. For the complete perspective, the NLN's current *Nursing Data Review 2007-2008: Baccalaureate, Associate Degree, and Diploma Programs* casts a wide net on all types of nursing programs, from doctoral through diploma, to determine rates of application, enrollment, and graduation.³ The survey creates a true picture of nursing education. Key findings include:

- **Growth of nursing programs declines.** Expansion in the number of prelicensure RN programs ground to a near halt between 2007 and 2008, with the nation adding only 15 additional programs, a less than 1 percent increase. This is a considerable slowdown in expansion, coming on the heels of almost 10 percent growth in the number of programs in 2006, and a smaller but still notable increase of almost 4 percent in 2007.
- **Key statistics reflect slowing growth.** Since 2003, nursing program admissions consistently moved upward, achieving an overall increase of over 36 percent during the period. However, in 2008, new admissions were down by almost 2 percent across all prelicensure program types.
- **Demand for admissions continues to outstrip supply.** Nearly one quarter (23.4 percent) of nursing programs of all types reported receiving more qualified applications than could be accepted in 2008. Among prelicensure programs, there was considerably more unmet demand for admissions; more than 119,000 qualified applications – or 39 percent of all qualified applications – were turned away from prelicensure programs in 2008. Moreover, more than one in three prelicensure programs (35 percent) had more qualified applications than openings.
- **Shortages of faculty and clinical placements constrain growth.** Among schools that did not accept all qualified applicants, shortages of faculty, clinical placements, and classroom space were reported as factors impeding the expansion of admissions. Almost two-thirds (64 percent) of doctoral programs and one-half of RN-BSN and master's programs identified insufficient faculty as the major constraint to expansion, in contrast to just one-third of prelicensure programs.

² Bureau of Labor Statistics, U.S. Department of Labor. *Employment Situation Summary – March 2010*. On the Internet at: <http://www.bls.gov/news.release/empsit.nr0.htm> (Accessed April 2, 2010).

³ National League for Nursing, (2010). *Nursing Data Review 2007-2008: Baccalaureate, Associate Degree, and Diploma Programs*. On the Internet at: <http://www.nln.org/research/slides/index.htm>. (Accessed April 2, 2010).

NURSE SHORTAGE AFFECTED BY FACULTY SHORTAGE

A strong correlation exists between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new RNs. Increasing the productivity of education programs is a high priority in most states, but faculty recruitment is a glaring problem that likely will grow more severe. Without faculty to educate our future nurses, the shortage cannot be resolved.

Through the beginning of this millennium, the nation's nurse faculty scarcity revealed a large crack in the health care infrastructure. A first indicator of this threatening situation was reported in the NLN's *Nurse Educators 2006: A Report of the Faculty Census Survey of RN and Graduate Programs*.⁴ Four years ago, the estimated number of budgeted, unfilled, full-time positions countrywide in 2006 was 1,390. That number represented a 7.9 percent vacancy rate in BSN and higher degree programs, which was an increase of 32 percent since 2002; and a 5.6 percent vacancy rate in ADN programs, which translated to a 10 percent rise in the same period. One year later, the NLN *Nursing Data Review 2006-2007* showed the vacancy situation rose appreciably. The study reported that nationwide more than 1,900 unfilled full-time faculty positions existed in 2007, affecting over one-third (36 percent) of all schools of nursing.⁵ In response, 84 percent of nursing schools attempted to hire new faculty in 2007-2008. Of those, 79 percent found recruitment "difficult" and almost one in three schools found it "very difficult." The two main difficulties cited were "not enough qualified candidates" (cited by 46 percent of schools), followed by the inability to offer competitive salaries (cited by 38 percent) compared to those salaries offered for clinical positions.

THE FEDERAL FUNDING REALITY

Today's undersized supply of appropriately prepared nurses and nursing faculty does not bode well for our nation, where the shortages are deepening health inequities, inflated costs, and poor quality of health care outcomes. The Title VIII Nursing Workforce Development Programs are a comprehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, and loans, scholarships and services that enable students to overcome obstacles to completing their nursing education programs. The Health Resources and Services Administration's Title VIII data below provide perspective on the current federal investments addressing the ongoing systemic problem of shortages.

Nurse Education, Practice, and Retention Grants (NEPR) – NEPR funds academic and continuing education projects enhancing the nursing workforce and improving nurse retention and quality of care. The Integrated Technology into Nursing Education and Practice (ITNEP) activity of this program supports development of faculty in the use of information and technologies, e.g., simulated learning, informatics, telehealth. In FY 2008, ITNEP affected 455 nurse educators. In FY 2009, seven cooperative agreements were funded, representing only a 20 percent success rate for the number of applications eligible and approved.

⁴ National League for Nursing. (July 2006). News release – *Nurse Educators 2006: A Report of the Faculty Census Survey of RN and Graduate Programs*. On the Internet at: <http://www.nln.org/newsreleases/nurseeducators2006.htm>.

⁵ National League for Nursing. (2009). *Nursing Data Review 2006-2007: Executive Summary*. On the Internet at: http://www.nln.org/research/slides/exec_summary_0607.pdf. Accessed April 2, 2010.

Advanced Education Nursing (AEN) Program – AEN supports infrastructure grants to schools of nursing for programs preparing advanced education nurses to practice as primary care providers and/or nursing faculty. In FY 2008, AEN supported the training of 5,649 graduate-level nursing students, and 20 of the grant programs focused on preparation of nurse educators. In FY 2009, 76 percent of the eligible applications were approved for funding, and 160 awards were made. The Advanced Education Nursing Traneeship (AENT) portion of this program awards grants to schools of nursing to assist primary or acute care nurse practitioners, nurse-midwives, nurse anesthetists, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, and other advanced level nursing specialties. In FY 2008, AENT grants supported 6,675 graduate nursing students, of which 200 graduates were prepared in nurse educator specialty programs. In FY 2009, 270 awards were made, or 100 percent of the eligible applications were approved for AENT funding.

Nursing Workforce Diversity (NWD) Program – NWD increases educational opportunities for individuals from disadvantaged backgrounds (including racial and ethnic minorities underrepresented in nursing) through scholarship or stipend support, pre-entry preparation, and retention activities. In FY 2008, 11,638 students were supported. In FY 2009, 70 percent of eligible applications were approved, resulting in 47 grants awarded.

Comprehensive Geriatric Education Program (CGEP) – CGEP funds training, curriculum development, faculty development and continuing education for nursing personnel who care for older citizens. In FY 2008, CGEP supported 6,514 nurses and nursing students. Twenty-seven grants, representing 60 percent of the eligible CGEP applications, were awarded in FY 2009.

CONCLUSION

The NLN can state with authority that the nursing shortage in this country will not be reversed until the concurrent shortage of qualified nurse educators is addressed. Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those in this country who will need our care. Without national efforts of some magnitude to match the health care reality facing our country today, a calamity in nurse education and in health care generally may not be avoided. The NLN urges Congress to *strengthen the Title VIII Nursing Workforce Development Programs by funding them to a level of \$267.3 million in FY 2011. We also recommend that the 10 percent requested increase be directed to the Title VIII programs that have not kept pace with inflation since FY 2005: Advanced Education Nursing, Nursing Workforce Diversity, Nurse Education, Practice and Retention, and Comprehensive Geriatric Education. These programs, which help expand nursing school capacity and increase patient access to care, would benefit were the requested 10 percent increase distributed in proportion to their FY 2010 funding levels.*

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**TESTIMONY OF
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**SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE
ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES**

**REGARDING FY11 APPROPRIATIONS FOR THE DEPARTMENT OF
HEALTH AND HUMAN SERVICES**

MAY 18, 2010

Mr. Chairman, thank you for the opportunity to submit testimony regarding the FY2011 budget for the National Heart, Lung and Blood Institute, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, and the Centers for Disease Control and Prevention. The National Marfan Foundation is grateful for the subcommittee's strong support of the NIH and CDC, particularly as it relates to life-threatening genetic disorders such as Marfan syndrome. Thanks in part to your leadership we are at a time of unprecedented hope for our patients.

It is estimated that 200,000 people in the United States are affected by Marfan syndrome or a related condition. Marfan syndrome is a genetic disorder of the connective tissue that can affect many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. It is a progressive condition and can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome is a weakening of the aorta. The aorta is the largest artery carrying oxygenated blood from the heart. Over time, many Marfan syndrome patients experience a dramatic weakening of the aorta which can cause the vessel to dissect and tear.

Early surgical intervention can prevent a dissection and strengthen the aorta and the aortic valves. If preventive surgery is performed before a dissection occurs, the success rate of the procedure is over 95%. If surgery is initiated after a dissection has occurred, the success rate drops below 50%. Aortic dissection is a leading killer in the United States, and 20% of the people it affects have a genetic predisposition, like Marfan syndrome, to developing the complication.

Fortunately, new research offers hope that a commonly prescribed blood pressure medication might be effective in preventing this frequent and devastating event.

FY11 APPROPRIATIONS RECOMMENDATIONS

NATIONAL INSTITUTES OF HEALTH

Mr. Chairman, NMF joins with other voluntary patient and medical organizations in recommending an appropriation of \$35 billion for the National Institutes of Health in FY11. This level of funding will ensure continued expansion of research on rare diseases like Marfan syndrome and build upon the significant investment provided to the NIH in the American Recovery and Reinvestment Act.

NATIONAL HEART, LUNG AND BLOOD INSTITUTE

A) Pediatric Heart Network Clinical Trial

NMF applauds the National Heart, Lung and Blood Institute for its leadership in advancing a landmark clinical trial on Marfan syndrome. Under the direction of Dr. Lynn Mahoney and Dr. Gail Pearson, the Institute's Pediatric Heart Network has spearheaded a multicenter study focused on the potential benefits of a commonly prescribed blood pressure medication (losartan) on aortic growth in Marfan syndrome patients.

Dr. Hal Dietz, the Victor A. McKusick Professor of Genetics in the McKusick-Nathans Institute of Genetic Medicine at the Johns Hopkins University School of Medicine, and the director of the William S. Smilow Center for Marfan Syndrome Research, is the driving force behind this groundbreaking research. Dr. Dietz uncovered the role that the growth factor *TGF-beta* plays in aortic enlargement, and demonstrated the benefits of losartan in halting aortic growth in mice. He is the reason we have reached this time of such promise and NMF is proud to have supported Dr. Dietz's cutting-edge research for many years.

Over the past four years, more than 500 Marfan syndrome patients (age 6 months to 25 years) have been enrolled in this study. Patients are randomized onto either losartan or atenolol (a beta blocker that is the current standard of care for Marfan patients with an enlarged aortic root). We are on schedule to meet the trial's enrollment target of 604 patients by the end of this year. This

is a noteworthy accomplishment in itself given the rarity of Marfan syndrome. We anxiously await the results of this first-ever clinical trial for our patient population. It is our hope that losartan will emerge as the new standard-of-care and greatly reduce the need for surgery in at-risk patients.

Mr. Chairman, NMF is proud to actively support the losartan clinical trial in partnership with the Pediatric Heart Network. Throughout the life of the trial we have provided support for patient travel costs, coverage of select echocardiogram examinations, and funding for ancillary studies. These ancillary studies will explore the impact that losartan has on other manifestations of Marfan syndrome.

B) Evaluation of Surgical Options for Marfan Syndrome Patients

Mr. Chairman, we are grateful for the subcommittee's recommendations in the FY10 bill encouraging NHLBI to support research on surgical options for Marfan syndrome patients.

For the past several years, the NMF has supported an innovative study looking at outcomes in Marfan syndrome patients who undergo valve-sparing surgery compared with valve replacement. Initial findings were published last year in the *Journal of Thoracic and Cardiovascular Surgery*. Some short term questions have been answered, most importantly that valve-sparing can be done safely on Marfan patients by an experienced surgeon. The consensus among the investigators however is that long-term durability questions will not be answered until patients are followed for 10 years.

As a result, the principal investigators involved in the study recently submitted an RO-1 grant proposal to the NHLBI seeking support for this effort. Confirming the utility and durability of valve sparing procedures will save our patients a host of potential complications associated with valve replacement surgery. We encourage the subcommittee to continue its support for this much-needed research in FY11.

C) NHLBI "Working Group on Research in Marfan Syndrome and Related Conditions"

In 2007, NHLBI convened a "*Working Group on Research in Marfan Syndrome and Related Conditions*." Chaired by Dr. Dietz, this panel was comprised of experts in all aspects of basic and clinical science related to the disorder. The panel was charged with identifying key recommendations for advancing the field of research in the coming decade. The recommendations of the Working Group are as follows ---

"Scientific opportunities to advance this field are conferred by technological advances in gene discovery, the ability to dissect cellular processes at the molecular level and imaging, and the establishment of multi-disciplinary teams. The barriers to progress are addressed through the following recommendations, which are also consistent with Goals and Challenges in the NHLBI Strategic Plan.

- Existing registries should be expanded or new registries developed to define the presentation, natural history, and clinical history of aneurysm syndromes.

- Biological and aortic tissue sample collection should be incorporated into every clinical research program on Marfan syndrome and related disorders and funds should be provided to ensure that this occurs. Such resources, once established, should be widely shared among investigators.
- An Aortic Aneurysm Clinical Trials Network (ACTnet) should be developed to test both surgical and medical therapies in patients with thoracic aortic aneurysms. Partnership in this effort should be sought with industry, academic organizations, foundations, and other governmental entities.
- The identification of novel therapeutic targets and biomarkers should be facilitated by the development of genetically-defined animal models and the expanded use of genomic, proteomic and functional analyses. There is a specific need to understand cellular pathways that are altered leading to aneurysms and dissections, and to develop robust in vivo reporter assays to monitor TGF β and other cellular signaling cascades.
- The developmental underpinnings of apparently acquired phenotypes should be explored. This effort will be facilitated by the dedicated analysis of both prenatal and early postnatal tissues in genetically-defined animal models and through the expanded availability to researchers of surgical specimens from affected children and young adults.

We look forward to working closely with NHLBI to pursue these important research goals and ask the Subcommittee to support the recommendations of the Working Group.

D) Specialized Centers of Clinical Oriented Research (SCCOR)

The National Marfan Foundation is grateful for NHLBI's 5-year support of the Specialized Center of Clinical Oriented Research in Thoracic Aortic Aneurysms and Dissections. This P-50 grant mechanism was an invaluable mechanism in the aneurysm field in moving research forward. It would be of great interest to the aortic disease scientific community to have this mechanism remain intact.

NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

NMF is proud of its longstanding partnership with the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Dr. Steven Katz has been a strong proponent of basic research on Marfan syndrome during his tenure as NIAMS director and has generously supported several "Conferences on Heritable Disorders of Connective Tissue." Moreover, the Institute has provided invaluable support for Dr. Dietz's mouse model studies. The discoveries of fibrillin-1, TGF-beta, and their role in muscle regeneration and connective tissue function were made possible in part through collaboration with NIAMS.

As the losartan trial continues to move forward, we hope to expand our partnership with NIAMS to support related studies that fall under the mission and jurisdiction of the Institute. One of the areas of great interest to researchers and patients is the role that losartan may play in

strengthening muscle tissue in Marfan patients. We would welcome an opportunity to partner with NIAMS on this and other research.

We are also thankful for the recent renewal of the Program Project (P-01) entitled "Consortium for Translational Research in the Marfan Syndrome" for the next five years. This grant mechanism has enabled, four institutions to share core laboratories and collaborate productively on projects to move research forward in an extremely efficient manner. The dissolution of the program project mechanism will be a great loss for these laboratories however; it is our hope that the new grant mechanism Centers of Research Translation (CORT) might be utilized in the same manner to keep the research at the forefront of the connective tissue field.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Mr. Chairman, we are very grateful to you and the subcommittee for your support of a Marfan syndrome awareness project currently being developed by the NMF and the CDC. One of the most important things we can do to prevent untimely deaths from aortic aneurysms is to increase awareness of Marfan syndrome and related connective tissue disorders. Our collaboration with the CDC in FY10 will enable us to expand our outreach to the general public and healthcare providers and ultimately save lives.

It is a hopeful time in our community as we reach out to at-risk populations about the cardiovascular complications associated with Marfan syndrome. Just last month, the American College of Cardiology and the American Heart Association issued landmark practice guidelines for the treatment of thoracic aortic aneurysms and dissections. The NMF is promoting awareness of the new guidelines in collaboration with other organizations through a new Coalition known as TAD; the Thoracic Aortic Disease Coalition. We hope to partner with the CDC in FY11 to increase awareness of the guidelines so all patients will be adequately diagnosed and treated.

For FY11, NMF joins with the CDC Coalition in recommending an appropriation of \$8.8 billion for the CDC. We also join with the Friends of the National Center on Birth Defects and Developmental Disabilities in recommending a funding level of \$163.5 million for NCBDD in 2011. NCBDD and its single-gene disorders program serve as the home within CDC for the Marfan syndrome community.

ABOUT THE NATIONAL MARFAN FOUNDATION

The NMF is a non-profit voluntary health organization founded in 1981. NMF is dedicated to saving lives and improving the quality of life for individuals and families affected by the Marfan syndrome and related disorders. The Foundation has three major goals: (i) to provide accurate and timely information about the Marfan syndrome to affected individuals, family members, physicians and other health professionals; (ii) to provide a means for those with Marfan syndrome and their relatives to share in experiences, to support one another and to improve their medical care and (iii) to support and foster research.

NATIONAL MINORITY CONSORTIA:

- Center for Asian American Media (415-863-0814)
- Latino Public Broadcasting ((814-847-9656)
- National Black Programming Consortium (212-234-8200)
- Native American Public Telecommunications (402-472-3522)
- Pacific Islanders in Communications (808-591-0059)

Submitted to the House Appropriations Subcommittee on Labor-HHS-Education

Regarding Corporation for Public Broadcasting FY 2013 Funding (FY 2011 Appropriations Act)

March 15, 2010

The National Minority Consortia (NMC) submits this statement on the FY 2013 appropriation for the Corporation for Public Broadcasting (CPB). The NMC is a coalition of five national organizations dedicated to bringing the unique voices and perspectives from America's diverse communities into all aspects of public broadcasting and to other media, including content transmitted digitally over the Internet. The role we fulfill in this regard has been crucial to public broadcasting's mission for over thirty years. We are unique as organizations and as a coalition of organizations in the services we provide in access, training and support for important and timely public interest content to our communities and to public broadcasting. We ask the Committee to:

- *Direct CPB to increase its efforts for diverse programming with commensurate increases for minority programming and for organizations and stations located within underserved communities;*
- *Direct CPB to establish a percentage basis for biennial funding of the National Minority Consortia to permit long range financial and strategic planning;¹*
- *Direct CPB to establish an annual "report card" on diversity to track efforts to better represent the full breadth of the American people and their experiences through public television, public radio and non-profit media online;*
- *Direct CPB to publish on the Internet clear and enforced guidelines for all CPB-directed funding, including funds jointly administered by PBS and NPR, and end the closed-door funding processes historically in place, especially as the current practices favor existing relationships and can be seen as biased against minority applicants, in particular.*

Report Language. We ask for Committee report language, specifically an addition to report language from the FY 2006 Appropriations Act (and also included in the FY 2007 Senate Appropriations report), which recognizes the contribution of the NMC and directs that the CPB partnership with us be expanded. The report stated:

¹ *Currently funding for the NMC, in the aggregate, represents only 1.2% of CPB's request. We suggest increasing that percentage to an amount equal to not less than 20% of the amount requested for television programming, or approximately \$20 million, to be split equally among the five groups listed here and beginning immediately upon enactment of this legislation.*

"The Committee recognizes the importance of the partnership CPB has with the National Minority Public Broadcasting Consortia, which helps develop, acquire, and distribute public television programming to serve the needs of African American, Asian American, Latino, Native American, Pacific Islander, and many other viewers. As many communities in the Nation welcome increased numbers of citizens of diverse ethnic backgrounds, the local public television stations should strive to meet these viewers' needs. With an increased focus on programming to meet local community needs, the Committee encourages CPB to support and expand this critical partnership." (S. Rpt. 109-103, p. 298)

We request that the above language be modified to direct CPB to increase its funding of the NMC and the various minority radio consortia to a level equal, in the aggregate, to 20% of funds allocated to television production.

FY 2013 Appropriation. We support a FY 2013 advance appropriation for CPB of \$604 million, which recognizes the need to develop content that reaches across traditional media boundaries, such as those separating television and radio. However, we feel strongly that should CPB receive this appropriation, CPB should be directed to engage in transparent and fair funding practices that guarantee all applicants equal access to these public resources. In particular, we urge Congress to direct CPB to insert language in all of its funding guidelines that encourages and rewards public media that fully represents and *reaches* a diverse American public.²

While public broadcasting continues to uphold strong ethics of responsible journalism and thoughtful examination of American history, life and culture, including the ways we are a part of a global society, it has not kept pace with our rapidly changing public as far as diversity is concerned. Members of minority groups continue to be underrepresented on both the programming and oversight levels within public broadcasting as well as on the content production side. There are fewer than five executives of diverse background at the highest levels in the three leading organizations within public broadcasting. This is unacceptable in America today, where minorities comprise over 35% of the population.

Public broadcasting has the potential to be particularly important for our nation's growing minority and ethnic communities, especially as we transition to a broadband-enabled, twenty-first century workforce that relies on the skills and talent of all of our citizens. While there is a niche in the commercial broadcast and cable world for quality programming about our communities and our concerns, it is in the public broadcasting sphere where minority communities and producers should have more access and capacity to produce diverse high-quality programming for national audiences. We therefore, urge Congress to insert strong language in this act to ensure that this is the case and that these opportunities are made available to minorities and other underserved communities.

² According to the 2008 Public Radio Tech Survey, 90 percent of public radio listeners are White. Of those, 84 percent are college-educated, with 48 percent having graduate degrees. This compares to just 9% of Americans who have postgraduate degrees. It is therefore mandatory that we prioritize actually "reaching" a diverse audience of Americans and not simply reflecting diverse and often misleading staffing numbers to measure public media's effectiveness in serving all of the American taxpayers that fund CPB.

About the National Minority Consortia. With primary funding from the Corporation for Public Broadcasting, the NMC serves as an important component of American public television as well as content delivered over the Internet. By training and mentoring the next generation of minority producers and program managers as well as brokering relationships between content makers and distributors (such as PBS, APT and NETA), we are in a perfect position to ensure the future strength and relevance of public television and radio television programming from and to our communities. However, these efforts are vulnerable because of chronic underfunding and lack of meaningful and ongoing representation within CPB's decision-making processes. This instability, coupled with what is essentially a decrease in our funding over time, are the primary reasons that have led to a public media that has become less diverse over the past five years.³

This is obviously not the case in the rest of America. With minority populations already estimated at over 35% of the total US population, it is more important than ever that our public institutions reflect this reality.

Individually, each Consortia organization is engaged in cultivating ongoing relationships with the independent producer community by providing technical assistance, program funding, programming support and distribution. Often the funding we provide is the initial seed money for a project, thus allowing it to develop. We also provide numerous hours of programming to individual public television and radio stations, programming that is beyond the production reach of most local stations. To have a real impact, we need funding that recognizes and values the full extent of minority participation in public life.

While the Consortia organizations work on projects specific to their communities, the five organizations also work collaboratively. An example of a joint production in which the NMC provided the initial seed money is "Unnatural Causes: Is Inequality Making Us Sick?" a multi-part series that uncovers the roots of racial and socio-economic disparities in health and spotlights community initiatives to achieve health equality. Our seed money enabled the project to go forward and to attract additional funding. We are also co-producers of and presenters in this series, which originally aired in 2008 and was rebroadcast just this year. Additionally, we jointly funded an online initiative around the Presidential Election in 2008 and continue to explore as a group other topics of national importance.

CPB Funds for the National Minority Consortia. The NMC receives funds from two portions of the CPB budget: organizational support funds from the Systems Support and programming funds from the Television Programming funds. The *organizational support funds* we receive from CPB are used not only for operations requirements but also for a broad array of programming support activities and for outreach to our communities and system-wide within public broadcasting. The *programming funds* we receive from CPB are re-granted to producers,

³ CPB funding for the NMC remained flat for 13 years until FY 2008, at approximately one million dollars per year per consortia. At that time, we received a one-time increase of \$150,000 per organization. In FY 2009, we received another one-time increase of approximately \$500,000 each, but have been told that does not reflect a permanent increase. Over this same 13-year period, CPB's budget nearly doubled.

used for purchase of broadcast rights and other related programming activities. Each organization solicits applications from our communities for these programming funds.

Below is information about our individual organizations.

Center for Asian American Media CAAM's mission is to present stories that convey the richness and diversity of Asian American experiences to the broadest audience possible. We do this by funding, producing, distributing and exhibiting works in film, television and digital media. Over our 25-year history we have provided funding for more than 200 projects, many of which have gone on to win Academy, Emmy and Sundance awards, examples of which are *Daughter from Danang*; *Of Civil Rights and Wrongs: The Fred Korematsu Story*; and *Maya Lin: A Strong Clear Vision*. CAAM presents the annual San Francisco International Asian American Film Festival and distributes Asian American media to schools, libraries and colleges.

Latino Public Broadcasting (LPB) supports the development, production and distribution of public media content that is representative of Latino people, or addresses issues of particular interest to Latino Americans. LPB provides a voice to the diverse Latino community throughout the United States. Since its creation in 1998 by Edward James Olmos, LPB has provided over 200 hours of programming to public television, including *Roberto Clemente*, the Sundance award winners *Farmingville* and *El General*, and Emmy nominated *The Life and Times of Frida Kahlo*. LPB has organized over 100 workshops for the advancement of Latino producers and launched the first Latino anthology series on public television, VOCES, which aired its second season in 2009 on PBS stations across the country. LPB has received the Imagen Award and the National Council of La Raza's Alma Award.

The National Black Programming Consortium (NBPC) develops, produces and funds television and more recently audio and online programming about the black experience for American public media outlets. Since its founding in 1979, NBPC has provided hundreds of broadcast hours documenting African American history, culture and experience to public television and launched major initiatives that have brought important public media content to diverse audiences. In 2006, NBPC launched the New Media Institute (NMI) a program designed to train makers of public media to provide real value to communities using digital platforms. Currently, NBPC is preparing to launch the Public Media Corps, a highly visible, national, broadband-based program designed to extend the reach of tax-payer funded diverse content into the digital realm, to recruit the next generation of content makers, innovators and other stakeholders coming from all of America's communities, and to empower all Americans with relevant, critical and timely information.

Native American Public Telecommunications (NAPT) shares Native stories with the world through support of the creation, promotion and distribution of Native media. Founded in 1977, through various media—public television, public radio, and the Internet—NAPT brings awareness of Indian and Alaska Native issues. Through the CPB-funded Production Fund, five to ten new projects are supported each year. Last year, we worked with *American Experience* in the award winning *We Shall Remain*, a five-part Native history series. NAPT operates the AIROS Native Network, a 24/7 Internet radio station that features music, news, interviews, documentaries and audio theater. We also feature downloadable podcasts with Native

filmmakers, musicians and Tribal leaders. VisionMaker Video is now the premier source for quality Native American educational and home videos. Profits made from video sales are invested in new NAPT productions. All aspects of our programs encourage the involvement of young people to learn more about careers in the media—to be the next generation of storytellers. Through our location at the University of Nebraska-Lincoln, we offer student employment, internships and fellowships. Reaching the general public and the global market is the ultimate goal for the dissemination of Native-produced media.

Pacific Islanders in Communications. Since 1991, PIC has delivered programs and training that bring voice and visibility to Pacific Islander Americans. PIC presented the broadcast premier of the award-winning film, *Whale Rider*, on PBS -- the story of young girl who confronts years of tribal tradition to fulfill her destiny as the leader of her people. Other PBS broadcasts include *Time and Tide* about the devastating effects of global warming on the Pacific Islands and *Polynesian Power* the story of Pacific Islanders in the NFL. Currently PIC is developing a multi-part series, *Expedition: Wisdom*, in partnership with the National Geographic Society. PIC offers a wide range of development opportunities for Pacific Island producers through travel grants, seminars and media training. Producer training programs are held in the U.S. territories of Guam and American Samoa, as well as in Hawai'i, on a regular basis.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and we thank Congress for support of our work on behalf of our communities.

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April 15, 2010

The Honorable David Obey
 Subcommittee on Labor, Health and Human Services, Education and Related Agencies,
 Committee on Appropriations
 Re: Funding for the National Institutes of Health

Mr. Chairman and Members of the Subcommittee:

On behalf of the National Postdoctoral Association (NPA), thank you for this opportunity to provide written testimony in regard to the Fiscal Year (FY) 2011 funding for the National Institutes of Health (NIH). The NPA has greatly appreciated your support of increased and consistent funding for the NIH and your support of new scientists. Specifically, we appreciated the language that accompanied the FY 2010 Bill H.R. 3293 and requested a 2-percent increase in NIH training stipends. We are writing today in regard to **the 6-percent increase in NIH training stipends** requested in the President's FY 2011 Budget.

Background: Postdocs are the Backbone of U.S. Science and Technology

According to estimates by The National Science Foundation (NSF) Division of Science Resource Statistics, there are approximately 89,000 postdoctoral scholars in the United States¹. The NIH and the NSF define a "postdoc" as: *An individual who has received a doctoral degree (or equivalent) and is engaged in a temporary and defined period of mentored advanced training to enhance the professional skills and research independence needed to pursue his or her chosen career path.* The number of postdocs has been steadily increasing. The incidence of individuals taking postdoc positions during their careers has risen, from about 25 percent of those with a pre-1972 doctorate to 46 percent of those receiving their doctorate in 2002–05². Moreover, the number of science and engineering doctorates awarded each year is steadily rising with doctorates awarded in the medical/life sciences almost tripling between 2003 and 2007³.

Postdocs are critical to the research enterprise in the United States and are responsible for the bulk of the cutting edge research performed in this country. Consider the following:

- Fully 43 percent of first authors on *Science* papers are postdocs.⁴
- According to the National Academies, postdoctoral researchers "have become indispensable to the science and engineering enterprise, performing a substantial portion of the nation's research in every setting."⁵

- Postdoctoral training has become a prerequisite for many long-term research projects.⁶ In fact, the postdoc position has become the *de facto* next career step following the receipt of a doctoral degree in many disciplines.
- The retention of women and under-represented groups in scientific research depends upon their successful and appropriate completion of the postdoctoral experience.
- Postdoctoral scholars carry the potential to solve many of the world's most pressing problems; they are the principal investigators of tomorrow.

Unfortunately, postdocs are routinely exploited. They are paid a low wage relative to their years of training and are often ineligible for workman's compensation, disability insurance, paid maternity or paternity leave, employer-sponsored medical benefits, and retirement accounts.

The National Postdoctoral Association (NPA) advocates for policies that support postdoctoral training. We advocate for policy change within the research institutions that host postdoctoral scholars. More than 150 institutions, including the NIH and the NSF, have adopted portions of the NPA's recommended practices.

Problem: Postdoc Salaries/Stipends Don't Meet Cost-of-Living Standards

The NIH leadership has been aware that these stipends are too low since 2001, after the publication of the results of the study *Enhancing the Postdoctoral Experience for Scientists and Engineers* conducted by The National Academies' Committee on Science, Engineering and Public Policy (COSEPUP). In response, the NIH pledged (1) to increase entry-level stipends to \$45,000 by raising the stipends at least 10 percent each year and (2) to provide automatic cost-of-living increases each year thereafter to keep pace with inflation.

Without sufficient appropriations from Congress, the NIH has not been able to fulfill its pledge. In 2007, the stipends were frozen at 2006 levels and since then have only been raised twice: by one percent each year in 2009 and 2010. The 2010 entry-level training stipend is \$37,740, the equivalent of a GS-8 position in the federal government (NIH Statement NOT-OD-10-047), despite the postdocs' advanced degrees and specialized technical skills. Furthermore, this stipend remains far short of the promised \$45,000. Certainly, it is not reflective of any cost-of-living increases.

The NPA's research has shown that the NIH training stipends are used as a benchmark by research institutions across the country for establishing compensation for postdoctoral scholars. In order to keep the "best and the brightest" scientists in the U.S. research enterprise, which is essential if the United States is to remain a global leader in this enterprise, the NPA believes that it is extremely important that Congress appropriate funding for the 6-percent increase in training stipends.

Please consider the following requests from scientists in other countries:

- In 2009, the NPA was approached by a scientist from Qatar for help in recruiting U.S. scientists, and the Qatar Foundation is prepared to offer compensation and benefits that would exceed those received by most postdocs in the United States.

- Scientists from Canada, China, Japan, and Australia, among other countries, have been seeking the NPA's advice and have asked the NPA to establish partnerships with their organizations.

And the following statistics:

- Although the 2007 U.S. expenditures on Research and Development (R&D) exceeded that of any other country/region, from 1996 to 2007, the U.S. R&D/GDP ratio held steady, while China's ratio doubled.⁷
- From 1996 to 2007, the R&D growth rate for the Asia/Pacific region increased from 24 to 31 percent, while the North American region's growth rate decreased from 40 to 35 percent.⁸
- From 1996 to 2007, the United States average annual growth of R&D expenditures averaged 5 percent, whereas China's average annual growth topped 20 percent.⁹

If the United States is to stay competitive in the global research enterprise, there needs to be continued, steady increases in NIH funding. If the U.S. research enterprise is to keep the best and brightest of postdoctoral scholars, there needs to be a significant increase in training stipends, sooner rather than later.

Solution: Keep the NIH's Original Promise to Raise the Minimum Stipends

As previously noted, for FY 2009 and FY 2010, NIH training stipends were increased by only 1 percent each year. While these increases were appreciated, the NPA would ask the Subcommittee to recognize that such small increases are simply not enough.

We ask the Subcommittee to fund the 6-percent increase as requested in the President's Budget (NIH Summary of the FY 2011 President's Budget):

Ruth L. Kirschstein National Research Service Awards:

A total of \$824.4 million, which is a 6.0 percent increase over the FY 2010, will be directed to training stipends. This increase sends a clear message to both existing and "would be" scientists that their efforts are valued.

Other Recommendations: Setting the Stage for Fair Compensation in the Coming Years

The NPA believes it is just and necessary to provide fair and appropriate compensation for the new scientists who will do the bulk of the research discovering cures for disease and developing new technologies to improve the quality of life for millions of people in the United States.

Accordingly, the NPA also recommends that the NIH:

- Review the base stipend amount in terms of what it should be today, nine years after the pledge was made.
- Develop a mechanism for providing cost-of-living adjustments for postdoctoral scholars located in regions with higher costs of living.
- Develop a funding mechanism to provide supplemental funding for postdoctoral scholars on research grants that would help to ensure equitable compensation for all of the NIH-funded postdoctoral scholars.

Finally, ten years have passed since the National Academies' COSEPUP study on the postdoc. The NPA applauds the changes that have taken place to improve the postdoc situation but also recognizes that many serious issues remain unresolved that may, and most probably will, negatively affect the future U.S. research workforce. Thus, the NPA recommends that the **House appropriates funds for a follow-up study that would provide information about the state of the postdoctoral community today.**

Thank you for your consideration.

Sincerely,

Cathee Johnson Phillips, M.A.
Executive Director, NPA

Stacy L. Gelhaus, Ph.D.
Chair, NPA Board of Directors

Ian Brooks, Ph.D.
Oversight Officer, NPA Board of Directors

Lorraine Tracy, Ph.D.
Vice Chair, NPA Board of Directors

Daniel Gorelick, Ph.D.
Treasurer, NPA Board of Directors

¹ National Science Foundation Division of Science Resource Statistics. (January 2010). Science and engineering indicators 2010. Arlington, VA: National Science Board.

² Ibid.

³ Ibid.

⁴ Davis, G. 2005. Doctors without orders. *American Scientist* 93(3, supplement). <http://postdoc.sigmaxi.org/results/>

⁵ COSEPUP. (June 2001). *Enhancing the postdoctoral experience for scientists and engineers*. Washington, D.C.: National Academy Press. p. 10.

⁶ COSEPUP. (June 2001). *Enhancing the postdoctoral experience for scientists and engineers*. Washington, D.C.: National Academy Press. p. 11.

⁷ National Science Foundation Division of Science Resource Statistics. (January 2010). *Science and engineering indicators 2010*. Arlington, VA: National Science Board.

⁸ Ibid.

⁹ Ibid.

NATIONAL PRIMATE RESEARCH CENTERS

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Written Statement for the Record
April 16, 2010

Prepared for the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

Regarding Fiscal Year 2011 Funding for the
National Institutes of Health
Department of Health and Human Services

The Directors of the eight National Primate Research Centers (NPRCs) respectfully submit this written testimony for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. The NPRCs appreciate the commitment that the Members of this Subcommittee have made to biomedical research through your strong support for the National Institutes of Health (NIH), and **recommend that you maintain this support for NIH in FY 2011 by providing an increase of 3.5 percent over FY 2010. Within this proposed increase the NPRCs also respectfully request that the Committee provide the National Center for Research Resources (NCRR) with the resources to continue a robust construction, renovation, and instrumentation grant program as begun through the American Recovery and Reinvestment Act, which as explained in this testimony, would help to ensure that the NPRCs and other animal research resource programs continue to serve effectively in their role as a vital national resource. Additionally, the NPRCs request that Congress provide NCRR no less than \$86,412,000 for the NPRC P51 (base grant) program, the amount equal to the President's budget request.** This program supports a portion of the operational costs of the eight NPRCs.

The NPRCs' Role as a National Resource and in the NIH Director's Five Themes

The NPRCs collaborate as a transformative and innovative network to support the best science and act as a resource to the biomedical research community as efficiently as possible. There is an exceptional return on investment in the NPRC program; ten dollars is leveraged for every one dollar of research support for the NPRCs. It is important to sustain funding for the NPRC program and the NIH as a whole to continue to grow and develop the innovative plan for the future of NIH. The NPRCs have a commitment from NCRR to develop a five year strategic plan to further enhance the capabilities of the NPRCs by building on current progress.

NIH Director Dr. Francis Collins laid out his vision for the future of the agency in terms of five "themes." The NPRCs as a consortium and as a resource to the biomedical research community currently play an important role in each of the five themes.

High Throughput Technologies. The NPRCs have been leading the development of a new Biomedical Informatics Research Network (BIRN) for linking brain imaging, behavior, and molecular informatics in non-human primate preclinical models of neurodegenerative disease. Using the cyberinfrastructure of the BIRN project for data-sharing, this project will link research and information to other primate centers, as well as other geographically distributed research groups.

Translational Research. Nonhuman primate models bridge the divide between basic biomedical research and implementation in a clinical setting. Currently, seven of the eight NPRCs are affiliated with and collaborate with the NCRR Clinical and Translational Science Awards (CTSA) Program through their host institution. Specifically, the nonhuman primate models at the NPRCs often provide the critical link between research with small laboratory animals and studies involving humans. As the closest genetic model to humans, nonhuman primates serve in the development process of new drugs, treatments, and vaccines, to ensure safe and effective use for the nation's public.

Using Science to Enable Health Care Reform. Animal models are an essential tool for bridging basic biomedical research and patient healthcare, and the NPRCs are a national resource which supports the achievement of this goal. The network of the eight NPRCs is taking a leadership role to encourage collaboration among researchers and health care providers across disciplines and institutions, with the goal of advancing biomedical knowledge and improving human health.

Global Health. Primate models are necessary for research on global infectious diseases. Primates have served as the best model for various types of HIV research, and their availability for use has resulted in at least 14 licensed anti-viral drugs for treatment of HIV infection. Primate models will continue to be necessary to defend the world against possible future epidemics such as SARS, West Nile Virus, and avian flu; and they are critical to current efforts to create vaccines for Ebola and Marburg viruses, and for infectious agents that could be used by terrorists. They also serve as the best model for development of vaccines for tuberculosis and malaria.

Although the number of chimpanzees essential to biomedical research is very few, chimpanzees remain the only valid research model for developing vaccines that prevent infection by the hepatitis C virus, from which millions of people worldwide suffer. Researchers do not embark upon the use of chimpanzees in research without due consideration, and are acutely aware of the ethical challenges and moral responsibilities of such research. But the fact remains that chimpanzee models have led to major medical advances; as a case in point, thanks to chimpanzee research, there are vaccines for hepatitis A and B.

Reinvigorating the Biomedical Research Community. The success of the U.S. Government's efforts in enhancing public health is contingent upon the quality of research resources that enable scientific research ranging from the most basic and fundamental to the most highly applied. Biomedical researchers have relied on one such resource – the National Primate Research Centers – for nearly 50 years for research models and expertise with nonhuman primates. The NPRCs are highly specialized facilities that foster the development of nonhuman primate animal

models and provide expertise in all aspects of nonhuman primate biology. NPRC facilities and resources are currently used by over 2,000 NIH funded investigators around the country.

The NPRCs are also supportive of getting students interested in the biomedical research workforce pipeline at an early age. For example, Yerkes NPRC supports a program that connects with local high schools and colleges in Atlanta, Georgia, and invites students to participate in research projects taking place at their field station location.

The Need for Facilities Support

As exemplified in the NPRCs' role in the future direction of NIH, the program is a vital resource for enhancing public health and spurring innovative discovery. In an effort to address many of the concerns within the scientific community regarding the need for funding for infrastructure improvements, the NPRCs support the continuation of a robust construction and instrumentation grant program at NCR.

The NPRCs thank Congress for appropriating \$1.3 billion of NIH Recovery Act funds for construction (C06), renovation (G20), and instrumentation (S10) grants. The number of applications received by NCR. illustrated the pent up need for facilities funding in the biomedical research community. Some of our centers received awards but a number of primate centers (and many other animal facilities) did not.

Animal facilities, especially primate facilities, are expensive to maintain and are subject to abundant "wear and tear." In prior years, funding was set aside that fulfilled the infrastructure needs of the NPRCs and other animal research facilities. **The NPRCs ask the Committee to provide an appropriation of no less than \$125 million to NCR. for construction and renovation of animal facilities through C06 and G20 programs.** Without proper infrastructure, the ability for animal facilities, including the NPRCs, to continue to meet the high demand of the biomedical research community will be unattainable.

Thank you for the opportunity to submit this written testimony and for your attention to the critical need for primate research and the continuation of infrastructure support, as well as our recommendations concerning funding for NIH in the FY 2011 Appropriations bill.

Sincerely,

Oregon NPRC
Nancy Haigwood, PhD
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David Anderson, DVM
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National Psoriasis Foundation

**Written Testimony to the House Labor, Health and Human Services and Education, and
Related Agencies (LHHS) Appropriations Subcommittee**

**Fiscal Year 2011 Psoriasis and Psoriatic Arthritis Research Funding through the
Department of Health and Human Services: National Institutes of Health and Centers for
Disease Control and Prevention**

**Submitted by: Richard Seiden, Chair, Board of Trustees
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April 16, 2010

Introduction and Overview

The National Psoriasis Foundation (the Foundation) appreciates the opportunity to submit written testimony for the record regarding fiscal year (FY) 2011 federal funding needs for psoriasis and psoriatic arthritis research. The Foundation serves as the world's largest patient-driven, non-profit, voluntary organization committed to finding a cure for and eliminating the devastating effects of psoriasis and psoriatic arthritis through research, advocacy and education. Psoriasis – the nation's most prevalent autoimmune disease, affecting as many as 7.5 million Americans – is a genetic, chronic, inflammatory, painful, disfiguring and life-altering disease that requires life-long, sophisticated medical intervention and care. Psoriasis imposes serious adverse effects on affected individuals and families, and 30 percent of people with psoriasis also develop psoriatic arthritis, which causes pain, stiffness and swelling in and around the joints and can lead to permanent disability. On average, 17,000 people with psoriasis live in every Congressional district.

The Foundation seeks to advance public and private efforts to improve treatment of psoriasis and psoriatic arthritis, identify a cure and ensure that all people with psoriasis and psoriatic arthritis have access to the medical care and treatment options they need to live normal lives with the highest possible quality of life. We work with policymakers at the local, state and federal levels to advance policies and programs that will reduce and prevent suffering from psoriasis and psoriatic arthritis. To that end, we are most grateful that, in FY 2010, Congress addressed the need to collect epidemiological data about psoriasis, by appropriating \$1.5 million for researchers at the Centers for Disease Control and Prevention's (CDC) National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) to begin the process of developing a national psoriasis and psoriatic arthritis data collection and patient registry. Considerable progress has been made, in the short amount of time since the initial appropriation, to develop this registry in a thoughtful and deliberate manner. We respectfully request that Congress continue to support this important initiative, by appropriating \$2.5 million in FY 2011 to allow this national psoriasis data collection initiative to move into the implementation phase. With additional FY 2011 funding, researchers can begin to collect data and increase our understanding of the co-morbidities, such as diabetes and heart attack, which are associated with

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psoriasis; examine the relationship of psoriasis to other public health concerns (e.g. smoking and obesity); and gain important insight into the long-term impact and treatment of psoriasis and psoriatic arthritis.

In addition, the Foundation supports the President's FY 2011 budget request for a \$1 billion increase in funding for the National Institutes of Health (NIH). The Foundation urges the Subcommittee to provide a total FY 2011 allocation of \$32.2 billion to NIH; this funding will help support new investigator-initiated research grants for genetic, clinical and basic research related to the understanding of the cellular and molecular mechanisms of psoriasis and psoriatic arthritis, as well as studies to expand on our nascent understanding of psoriasis and psoriatic arthritis patients' myriad co-morbid conditions.

The Impact of Psoriasis and Psoriatic Arthritis

Psoriasis typically first strikes between the ages of 15 and 25, but can develop at any time and usually lasts a lifetime. Total direct and indirect health care costs of psoriasis are calculated at more than \$11.25 billion annually, with work loss accounting for 40 percent of the cost burden. There is mounting evidence that people with psoriasis are at elevated risk for myriad other serious, chronic and life-threatening conditions. Although data still are emerging on the relationship of psoriasis to other diseases and their ensuing costs to the medical system, it is clear that psoriasis goes hand-in-hand with psoriatic arthritis and other co-morbidities, such as Crohn's disease, diabetes, metabolic syndrome, obesity, hypertension, heart attack, cardiovascular disease, and liver disease. Recent studies have found that people with severe psoriasis have a 50 percent higher mortality risk and die three to six years younger than those who do not have psoriasis. Studies have found that psoriasis causes as much disability as other major chronic diseases, and individuals with psoriasis are twice as likely to have thoughts of suicide as people without psoriasis or with other chronic conditions.

Despite some recent breakthroughs, many people with psoriasis and psoriatic arthritis remain in need of effective, safe, long-term and affordable therapies to allow them to live normally and improve the overall quality of their lives. Due to the nature of the disease, patients have to cycle through available treatments, which often stop working. While there are an increasing number of methods to control the disease, there is no cure. Often the treatments have serious side effects and can pose long-term risks for patients (e.g., suppress the immune system, deteriorate organ function, etc.). The lack of viable, long-term methods of control for psoriasis could be addressed through an increased federal commitment to epidemiological, genetic, clinical and basic research. NIH and CDC research, taken together, hold the key to improved treatment of these diseases, better diagnosis of psoriatic arthritis and eventually a cure for psoriatic conditions.

The Role of CDC in Psoriasis and Psoriatic Arthritis Research

Despite our increased understanding of the auto-immune underpinnings of psoriasis and its treatments, there is a dearth of population-based epidemiology data on psoriatic disease. The

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majority of existing epidemiological studies of psoriasis are based on case reports, case series and cross-sectional studies. Several analytical studies have been performed to identify potentially modifiable risk factors (e.g. smoking, diet, etc.) and some have yielded conflicting, or inconsistent, results. In addition, most case-controlled studies have been hospital-based, or specialty clinic-based, and, therefore, are limited in their value. Broadly-representative population-based studies of psoriasis are lacking and needed.

There is enormous opportunity to investigate the epidemiology of psoriasis, as there are still wide gaps in our knowledge of this disease. For example, there is a critical need to better understand the natural progress of chronic plaque psoriasis in order to identify which patients may experience spontaneous remissions and which patients may experience flares of their disease – and when and why. Large, broadly-representative population-based studies can expand our understanding of the potential risk factors for developing psoriasis, and future interventional trials can determine if altering modifiable risk factors, such as smoking and obesity, leads to a lower risk of psoriasis. Research into triggers and causes of psoriatic disease is also likely to be useful in determining advancements for other auto-immune disorders. Finally, determining the relative importance of psoriasis, its treatments and its associated behaviors with the risk of developing co-morbidities – such as cardiovascular disease, cancer and other diseases – will allow health professionals to better counsel patients and help them interpret long-term safety of novel therapies for psoriasis. The data collection and registry underway at the CDC will significantly advance our understanding of psoriatic disease and help answer some of the most pressing and perplexing questions facing researchers, clinicians and patients.

Psoriasis and Psoriatic Arthritis Research at NIH

It has taken nearly 30 years to understand that psoriasis is, in fact, not solely a disease of the skin but also of the immune system. In recent years, scientists have finally identified the immune cells involved in psoriasis. The last decade has seen a surge in our understanding of these diseases accompanied by new drug development. Scientists are poised as never before to make major breakthroughs.

Within the NIH, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Center for Research Resources (NCRR), the National Human Genome Research Institute (NHGRI) and the National Institute of Allergy and Infectious Diseases (NIAID) are the principal federal government agencies that currently support – or have funded – psoriasis research. Additionally, research activities that relate to psoriasis or psoriatic arthritis also have been undertaken at the National Cancer Institute (NCI); however, the Foundation maintains that many more NIH institutes and centers have a role to play, especially with respect to the myriad co-morbidities of psoriasis, as noted earlier. Although overall NIH funding levels improved for psoriasis research in FY 2010, and funding was boosted through stimulus funding awards of \$3 million in FY 2009 and (an estimated) \$2 million in FY 2010, the Foundation remains concerned that, generally, total NIH funding is not keeping pace with psoriasis and psoriatic arthritis research needs. Further, the federal government's investment in psoriasis and psoriatic arthritis research is not commensurate with the impact of the disease. An analysis of

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longitudinal federal funding data shows that, on average, NIH has spent approximately \$1.00 per person with psoriasis – per year – over the past decade. We commend NIH for the increased FY 2009 psoriasis research investment, which is currently estimated at approximately \$1.70 per psoriasis patient. According to Psoriasis Foundation scientific advisors, approximately \$37.5 million in NIH sponsored grants (about \$5 per psoriasis patient per year) over five years is the federal biomedical investment needed to achieve the next phase of progress toward improved psoriasis and psoriatic arthritis treatments and a cure.

Adequate investment in psoriasis and psoriatic arthritis research in FY 2011 and beyond is imperative, because a rare convergence of findings reached through various research studies only recently has elucidated new ideas about the mechanisms involved in psoriasis. Greater funding of genetics, immunology and clinical research focused on understanding the mechanisms of psoriasis and psoriatic arthritis is needed. Key areas for additional support and exploration include: studying the genetic susceptibility of psoriasis; developing animal models of psoriasis; identifying the environmental and lifestyle triggers for psoriasis; understanding the relationship of psoriasis to co-morbidities, such as heart attack, diabetes, increased mortality and lymphoma; identifying and examining immune cells and inflammatory processes involved in psoriasis; examining the relationship between psoriasis and mental illnesses, such as depression and suicidal ideation; and elucidating psoriatic arthritis specific genes and other biomarkers.

Funding Request Summary

The Foundation recognizes that Congress and the nation currently face unprecedented fiscal challenges. However, we also believe that greater FY 2011 investment in biomedical and epidemiologic research at NIH and CDC will prove stimulative to the economy, by supporting researchers and academic institutions across the nation. Further, researchers are poised, as never before, to bear fruit with regard to the development of new, safe, effective and long-lasting treatments and – ultimately – a cure for psoriasis and psoriatic arthritis. We thank the Subcommittee in advance for providing the following FY 2011 funding allocations:

- \$2.5 million to the NCCDPHP within the CDC to continue to collect data on psoriasis and psoriatic arthritis and to implement a patient registry to improve the knowledge base of the longitudinal impact of these diseases on the individuals they affect, as well as increase understanding of disease triggers and co-morbid conditions; and
- \$32.2 billion to NIH and its institutes and centers with encouragement to expand their psoriasis and psoriatic arthritis research portfolios, with an emphasis on understanding more about common co-morbid conditions.

Conclusion

On behalf of the Foundation's Board of Trustees and the 7.5 million individuals who suffer from psoriasis and psoriatic arthritis, whom we represent, thank you for affording us the opportunity to submit written testimony regarding the FY 2011 funding levels necessary to ensure that our

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nation adequately addresses the needs of those who suffer with psoriasis and psoriatic arthritis, by improving therapies and eventually finding a cure. We believe that additional research undertaken at the NIH, coupled with epidemiologic efforts at the CDC, will help advance the nation's efforts to improve treatments and identify a cure for psoriatic conditions. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to, and consideration of, our FY 2011 requests.

**NATIONAL REACH COALITION
FOR THE ELIMINATION OF HEALTH DISPARITIES**
c/o Community Health Councils, Inc. • 3731 Stocker Street, Suite 201 • Los Angeles, CA 90008

Public Record Testimony of the National REACH Coalition

Regarding FY 2011 for the Racial and Ethnic Approaches to Community Health (REACH) Program

Presented to the
United States House of Representatives Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies

April 16, 2010

The National REACH Coalition represents more than 40 communities and coalitions in 22 states working to eliminate racial and ethnic health disparities and improve the health of African American, Asian Pacific Islander, Native American and Latino populations and communities. The coalition is an outgrowth of the Racial and Ethnic Approaches to Community Health (REACH U.S.) 2010 initiative, started a decade ago by the Centers for Disease Control and Prevention (CDC). REACH programs are on the front lines, providing coordination and leadership for the advancement and translation of community-based participatory research into evidence-based practices, policies and community empowerment.

For the FY 2011 funding cycle the National REACH Coalition encourages the Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) Subcommittee to increase funding for the Racial and Ethnic Approaches to Community Health program to \$60 million, an increase of \$20.356 million over FY 2010.

The NRC gratefully acknowledges the strong bipartisan support that the Senate Subcommittee on Labor, Health and Human Services and Education has provided to the REACH U.S. program in recent years, most REACH programs were not eligible for additional funding provided by the American Recovery and Reinvestment Act and yet are working in communities that are among the hardest hit by the recession. With significant budget challenges at the state/local levels,

REACH programs provide an important safety net to help eliminate racial and ethnic health disparities and close the health equity gap.

Chronic diseases are the nation's leading causes of morbidity and mortality and account for 75% of every dollar spent on health care in the U.S. Collectively, they account for 70% of all deaths nationwide. Thus, it is highly likely that nearly 3 of 4 persons living in your district will be likely to develop a chronic condition requiring long-term and costly medical intervention. Moreover, chronic diseases account for the largest health gap among racial and ethnic minority populations. African Americans have higher mortality rates for cardiovascular disease and stroke, and cancer of the lung, colon/rectum, breast, cervix, and prostate than Whites, American Indians/Alaska Natives, Asian/Pacific Islanders, and Hispanic Americans.

REACH U.S. programs are working hard to eliminate these health disparities and many have proven success in their communities. Collectively as the National REACH Coalition, our programs have engaged hundreds of local coalition members and touched the lives of thousands of program participants in this nationwide campaign against health disparities. As a result, the REACH communities are testing, evaluating and implementing practice and evidence-based interventions that reduce the human and financial cost of these preventable diseases and associated risk factors by:

- **In South Carolina, the REACH Charleston and Georgetown Diabetes Coalition** reports that a 21% gap in blood sugar testing between African Americans and whites has been virtually eliminated. Amputations among African-American males with diabetes have been reduced by over 33%. Each avoided amputation avoids at least \$40,000 in expenditures; expanding this program could substantially reduce South Carolina's annual diabetes-related financial burden of more than \$900 million.
- **The REACH for Wellness program in Georgia's Atlanta Empowerment Zone** reports that from 2002 to 2004 the percentage of adults who regularly participated in moderate to vigorous physical activity increased from 25.4% to 28.7%; the percentage who reported checking their total blood cholesterol increased from 69.1% to 79.7%, and the percentage of adults who smoked decreased from 25.8% to 20.8%.

- The **REACH Alabama Breast and Cervical Cancer Coalition** in Macon County reports that disparities in mammography screening between white and African American women decreased from 15% to 2% from 1998 to 2003.
- In **Massachusetts, the Greater Lawrence Family Health Center**, a REACH Center of Excellence in Eliminating Health Disparities, has been able to demonstrate long-term disparity reductions among Latinos on five measures of diabetic care and outcomes.
- **Data from the REACH Risk Factor Survey** show that the REACH program is having a significant impact in key areas of risk reduction and disease management:
 - From 2001 to 2004, **African Americans** transitioned from being less likely to more likely than whites to have their cholesterol checked.
 - In REACH communities, the sizable gap in cholesterol screening between **Hispanics** and the national average is closing.
 - In REACH communities, the proportion of **American Indians** with high blood pressure who take medication increased from 67% in 2001 to 74% in 2004.
 - Cigarette smoking among **Asian men** in REACH communities decreased from 35% in 2001 to 24% in 2004.

REACH U.S. communities have spent the last decade leveraging CDC funding with public private partnerships in order to effectively address health disparities. Using innovative science-based approaches we have demonstrated that health disparities once considered expected are not intractable. REACH U.S. has provided a sound return on investment, but we could do a lot more. In 2007, more than **200 communities** applied for funding in the last CDC REACH U.S. program application cycle, but only 40 were funded. While we are extremely grateful for the \$4 million increase REACH U.S. received in FY 2010, without additional support REACH U.S. will not be able to extend its successful, cost-effective evidence- and practice-based programs to communities bearing a disproportionate share of the national chronic disease burden.

Providing a \$20.356 million increase, for a total of \$60 million in FY 2011 for REACH U.S. programs will ensure investment and sustainability in the bread and butter of prevention and wellness programs - community-led and community-driven interventions. Furthermore, health disparities and health equity will continue to be addressed and REACH U.S. programs will have

the ability to be expanded in our nation's most underserved communities. We strongly urge the Committee to consider this request to strengthen the capacity of the REACH U.S. program.

We thank you for this opportunity to present our views to this Subcommittee. We look forward to working with you to improve the health and safety of all Americans.



**National Recreation
and Park Association**

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**Written Testimony of Barbara Tulipane, CEO
submitted for the record on behalf of
The National Recreation and Park Association
House Appropriations Subcommittee on Labor, Health and Human Services and
Education**

April 9, 2010

Thank you Chairman Obey, Ranking Member Tiahrt, and other honorable members of the committee for the opportunity to submit written testimony on the importance of funding the Centers for Disease Control and Prevention's (CDC) Healthy Communities Program at \$30 million in the FY 2011 Labor-HHS-Education Appropriations bill. NRPA is a 501(c)3 national non-profit organization with more than 21,000 members. We represent both citizens and park and recreation professionals. Our mission is to advance parks, recreation and environmental conservation for the benefit of all people. Because we represent the public park and recreation agencies in the United States, we touch the lives of over 300 million people in virtually every community. Park and recreation agencies play a major role in the fight against obesity and are poised and capable of doing even more through the creation of new cross-cutting partnerships that promote health lifestyle choices for children and adults.

Our nation currently faces an obesity epidemic that is claiming the lives of adults and children. According to the CDC, the obesity rate in children ages 6 to 11 doubled from 6.5 percent in 1980 to 17.0 percent in 2006; and tripled among those ages 12 to 19 to 17.6 percent during the same time period. More than one-third of U.S. adults – over 72 million people - were obese in 2005-2006.

Obesity also has a crippling effect on our nation's economy and is largely responsible for the exuberant rise in health care costs. CDC reports that data from the 1998 and 2006 Medical Expenditure Panel Surveys (MEPS) revealed that obesity increased medical costs by 37 percent from 1998 to 2006. A 2009 study released by RTI, a non-profit research firm, showed that obese Americans cost the country about \$147 billion in weight-related medical bills in 2008, double what it was a decade ago. Obesity now accounts for about 9.1% of medical spending in our country.

The obesity and chronic disease epidemics plaguing our nation did not manifest themselves overnight. These epidemics grew to be national issues of concern by impacting one individual, one family, and one community at a time. A multitude of

factors such as lack of physical activity, poor diet, and excessive tobacco and alcohol use have led to this national epidemic. The good news is that many of the health risk factors that contribute to the development of chronic disease and obesity are preventable. However, the only way we will truly reduce obesity is to employ a comprehensive strategy that addresses these factors where people live, work, learn and recreate. In order for us to effectively combat these epidemics, local communities must be armed with the necessary tools and resources to implement policy, environmental and systematic changes geared towards promoting increased physical activity, nutritious foods, and the prevention of chronic disease in children, youth, and adults.

Investment in prevention and wellness was one of President Obama's eight core principles guiding health care reform. Congress also stressed the importance of prevention at the community level throughout the health reform debate and through inclusion of various prevention measures in the Patient Protection and Affordable Care Act and Education Affordability Reconciliation Act. The economics of community level prevention are clear. As noted by the Trust For America's Health, for an investment of \$10 per person per year in proven community-based programs to increase physical activity, improve nutrition, and prevent smoking and other tobacco use, the country could save more than \$16 billion annually within five years. This is a return of \$5.60 for every \$1 spent. Prevention programs provide proven returns on investment. We are asking this committee to further invest in prevention through increased FY11 appropriations for CDC's Healthy Communities Program.

Through its Healthy Communities program, CDC facilitates the collaboration of local and state health departments, national organizations with extensive reach into communities and a wide range of community leaders and stakeholders to develop, activate and spread policy, systems and environmental changes that prevent chronic disease by changing behavior and increasing the opportunities for healthier lifestyles. These community leaders and stakeholders represent local elected officials, city and county health officials, tribal programs, parks and recreation departments, local YMCAs, health-related coalitions, and education, business, health, planning, and transportation sectors. This collaboration results in proven community-based programs and environmental changes that encourage people to be more physically active, improve nutrition, and abstain from tobacco use.

To date, more than 240 communities have received funding and technical support through CDC's Healthy Communities Program which has resulted in measurable changes at the local level. An additional 170 communities will receive funding to improve the health of their communities during the next three years.

Chicago, Illinois is a great example of the impact of the Healthy Communities program. The city has noted that 26 percent of their children and 25 percent of their adult populations are obese by national standards. Contributing to the poor health of this community is the lack of opportunities for physical activity and the fact that the west side of Chicago lacks grocery stores which has caused it to become a "food desert". This, in turn causes residents to utilize fast food chains and convenience stores as a main source

of nourishment. Recognizing the health and financial implications of an obese population, Chicago is taking proactive steps to ensure a healthier a community. The park district has introduced new fitness classes in parks throughout the city and is now offering a minimum of 60 minutes of moderate to vigorous activity for all children's programs offered through parks. Through the leadership of the Mayor's office, a healthy vending policy has been initiated at all park facilities and the park district is implementing community produce gardens which will be maintained by local youth. Additionally, smoking has been banned on all Chicago Park District Property, indoors and out including beaches. Thanks to funding provided through CDC's Healthy Communities program, the city of Chicago will be able to implement more policy, systems and environmental changes, such as these, to combat chronic disease and obesity throughout the city.

Other success stories point to more than anecdotal program successes. Healthy Communities supports a broad coalition of stakeholders in Salamanca, New York that are implementing a city ordinance banning a smoking in all city parks and on playgrounds. Similarly, in Pierre, SD, the park and recreation department is working with schools and parent teacher organizations to promote healthy eating practices by updating school wellness policies. The new policy will focus on providing more fruits, vegetables, and whole grains in menu options, and implementing creative practices such as "sugar-free zones" in schools.

Funding for the CDC's Healthy Communities program is vital to successfully combating chronic disease and obesity at the local level. Previous funding levels have been inadequate. The Healthy Communities program has gone from \$46.6 million in FY05 to only \$22.7 million in FY10. As a result, hundreds of eligible communities have applied for highly competitive projects but remain unfunded due to limited federal resources.

Given the health implications and the fiscal hardship associated with chronic disease and obesity, we can no longer afford to be a nation that simply treats the problem. Now, more than ever Congress must increase its investment in community prevention programs such as this. NRPA respectfully requests that this committee provide increased funding for CDC's Healthy Communities program to \$30 million in the FY11 appropriations bill. Thank you for this opportunity to submit testimony. Please feel free to contact Stacey Pine, Chief Government Affairs Officer, in NRPA's Public Policy Office at 202-887-0290 with any questions you may have.

**National Resource Center on AD/HD
(Attention-Deficit/Hyperactivity Disorder)**

Testimony Prepared for the United States House Committee on Appropriations,
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

For more information, please contact:

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Background:

At the Centers for Disease Control and Prevention (CDC) 1999 conference titled "*Attention Deficit Hyperactivity Disorder: A Public Health Perspective*," over 150 experts gathered to discuss the public health concerns related to AD/HD and to explore areas for future research. The conference developed a public health research agenda which included recommendations on the establishment of: a resource for both professionals and the public regarding what is known about the epidemiology of AD/HD; an avenue of dissemination of educational materials related to the diagnosis of and intervention opportunities for AD/HD to primary care physicians, nurse practitioners, physicians assistants, mental health providers and educators; collaborations with other organizations to educate and promote what is known about AD/HD interventions, appropriate standards of practice, their effectiveness, and their safety; and a resource to the public for accurate and valid information about AD/HD and evidence-based interventions.

Congress responded to this research agenda in FY 2002 by providing resources for the CDC to begin a partnership with CHADD¹ to develop the *National Resource Center on AD/HD* (NRC) -- a significant development in recognizing the unique challenges faced by individuals with AD/HD across the lifespan.

The NRC's goals include improving the health and quality of life of individuals with AD/HD and their families; raising awareness and facilitating access to scientifically valid information and support services; and improving the understanding of the impact of AD/HD among healthcare specialists, educators, employers, and individuals with AD/HD. The NRC fulfills these goals by disseminating evidence-based research on AD/HD through a variety of mechanisms, including:

- a Web site (www.help4adhd.org) receiving on average 130,000 visits each month;

¹ Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) was founded by parents in 1987 in response to the frustration and sense of isolation experienced by parents and their children. CHADD is the leading national non-profit organization for children and adults with AD/HD, providing the public and providers with education, advocacy and support.

- a national call center, staffed by five professional health information specialists, including one bilingual health information specialist. The health information specialists responded to 9,364 individual inquiries during the last year on 17,115 different topical issues from parents, adults with AD/HD, mental health professionals, and educators;
- partnerships with minority health organizations to reach underserved populations;
- a series of over 25 “*What We Know*” fact sheets on AD/HD, in both English and Spanish; and
- a comprehensive library and online bibliographic database of over 4,100 evidence-based journal articles and reports on AD/HD.

The overwhelming demand for information and support on AD/HD by the public and the professional community has created an unprecedented need for additional resources to keep pace with the requests for information received by the NRC and to provide outreach and resources to unserved and underserved populations.

What is AD/HD?

A 2005 report by the CDC found that parents reported approximately 7.8 percent of school-age children (4 to 17 years) had a diagnosis of Attention-Deficit/Hyperactivity Disorder (AD/HD).² Other evidence-based studies have documented that more than 70 percent of children with AD/HD will continue to experience symptoms of AD/HD into adolescence, and almost 65 percent will exhibit AD/HD characteristics as adults.³ In addition, up to two-thirds of children with AD/HD will have at least one co-occurring disability with fifty percent of these children having a co-occurring learning disability.

Only half of all children with AD/HD receive the necessary treatment, with lower diagnostic and treatment rates among girls, minorities and children in foster care. If untreated or inadequately treated, AD/HD can have serious consequences, increasing an individual’s risk for school failure, unemployment, interpersonal difficulties, other mental health disorders, substance and alcohol abuse, injury, antisocial and illegal behavior, contact with law enforcement, and shortened life expectancy.⁴ The availability of appropriate services and access to treatment can help individuals with AD/HD avoid negative outcomes and lead successful lives.

FY 2011 Appropriations Request:

The NRC has met and continues to meet the goals of improving the health and quality of life for individuals with AD/HD and their families; raising awareness and facilitating access to evidence-based information and support services; and improving the understanding of the impact of AD/HD among healthcare specialists, educators, employers, and individuals with AD/HD.

Both the National Institutes of Health Consensus Conference on AD/HD (Nov. 1998) and the

² Centers for Disease Control and Prevention. (2005). *Mental Health in the United States: Prevalence of Diagnosis and Medication Treatment for Attention-Deficit/Hyperactivity Disorder*. Retrieved March 25, 2005, from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5434a2.htm>.

³ Dulcan, M., and the Work Group on Quality Issues. (1997, October). AACAP official action: Practice parameters for the assessment and treatment of children, adolescents, and adults with Attention-Deficit/Hyperactivity Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, Supplement, 36*(10), 85S-121S.

⁴ Barkley, R. A. (1997). *ADHD and the nature of self-control*. New York: The Guilford Press.

Centers for Disease Control and Prevention Conference on Public Health and AD/HD (Sept. 1999) concluded that AD/HD is a serious public health concern that needs to be addressed because of the potential economic burden associated with AD/HD. Numerous peer reviewed journal articles have documented the significant health care cost of individuals with AD/HD.⁵

In “*AD/HD in Adults: What the Science Says*,” Barkley, Murphy & Fisher discuss the results of the few empirical studies that have been conducted regarding occupational functioning of clinic-referred adults with AD/HD.⁶ “Although opinions abound on the topic in trade books on ADHD in adults, there is very little research on the occupational functioning of clinic-referred adults with ADHD” (p. 276). One study conducted at UMASS found that adults with a diagnosis of AD/HD are more likely to self-report and have employers report difficulties with occupational functioning than their clinic-referred or community counterparts. In addition, the Milwaukee study (2006) found that individuals diagnosed as having AD/HD as children that persists until age 27 tend to be more severely affected in occupational functioning than clinic-referred adults or community counterparts. In addition, another study conducted by Biederman & Faraone (2006) concluded that individuals with AD/HD are less likely to be employed full time (34 percent of individuals with AD/HD compared to 59 percent of individuals without AD/HD).⁷ In addition, the study found that the household incomes of adults over the age of 25 were significantly lower among individuals with AD/HD when compared to individuals without AD/HD regardless of academic achievement or personal characteristics. The results of these three studies indicate the need for further research into the impact of AD/HD on the occupational functioning of adults and how best to reasonably accommodate their disability in the workplace because over 30 percent of requested accommodations are at no cost to the employer but yet according to Biederman & Faraone the total cost of work loss among men and women with AD/HD is \$2.6 billion, or 53 percent of the total \$13 billion cost of adult ADHD in the United States.

Last year, the AD/HD line item was funded at \$1.751 million. We are requesting a \$400,000 increase in the AD/HD line item, which will result in a \$200,000 increase in the NRC. Historically, half of the increase to the AD/HD line item has been used to fund research on AD/HD. The \$200,000 increase to the NRC will allow the NRC to further develop its outreach to the African-American and Hispanic-Latino communities, and most importantly during this current economic climate to initiate an employment information specialist service.

⁵ Cuffe, S.P., Moore, C.G., & McKeown, R. (2009). ADHD and health services utilization in the National Health Survey. *Journal of Attention Disorders*, 12(4), 330-340.; Chan, E., Zhan, C., & Homer, C.J. (2002). Health care use and costs for children with Attention-Deficit/Hyperactivity Disorder. *Archives of Pediatrics & Adolescent Medicine*, 156, 504-511.; Rowland, A.S., Umbach, D.M., Stallone, L., Naftel, J., Bohlig, E.M., & Sandler, D. P. (2002). Prevalence of medication treatment for Attention Deficit – Hyperactivity Disorder among elementary school children in Johnston County, North Carolina. *American Journal of Public Health*, 92(2), 231-234.; Ray, T.G., Levine, P., Croen, L.A., Bokhari, F.A.S., Hu, T., & Habel, L.A. (2006). Attention-Deficit/Hyperactivity Disorder in children. *Archives of Pediatrics & Adolescent Medicine*, 160, 1063-1069.

⁶ Barkley, R.A., Murphy, K.R., & Fischer, M. (2008). *ADHD in Adults: What the Science Says*. New York: The Guilford Press.

⁷ Biederman, J., & Faraone, S.V. (2006). *The effects of attention-deficit/hyperactivity disorder on employment and household income*. *MedGenMed*, 8(3),12, Retrieved March 25, 2005, from <http://www.medscape.com/viewarticle/536264>.

Requested Report Language for FY 2011:

The Committee continues to support the activities of the CDC's NCBDDD and the National Resource Center (NRC) on AD/HD and has provided \$2,151,000 to continue this support, including \$1,075,500 to maintain and expand the activities at the NRC as it responds to the overwhelming demand for information and support services, reaches special populations in need, and most importantly during this current economic climate, provides support for a health information specialist focused on employment to assist individuals with AD/HD to lead successful, economically self-sufficient, and independent lives integrated into their communities with the necessary accommodations and supports.

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**Testimony of the National Rural Health Association (NRHA)
Concerning HRSA's Programs Impacting Rural Health**
*Submitted for the Record to the House Appropriations Subcommittee on
Labor, Health and Human Services, and Education – April 16, 2010*

The National Rural Health Association (NRHA) is pleased to provide the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on FY 2011 funding levels for programs with a significant impact on the health of rural America.

The NRHA is a national nonprofit membership organization with more than 20,000 members that provides leadership on rural health issues. The Association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research. The NRHA membership consists of a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health.

The NRHA is advocating for full funding for a group of rural health programs that assist a large percentage of rural communities in building a stronger health delivery system for the future. Most importantly, these programs build capacity in the rural health care delivery system, capacity that will be absolutely necessary with the influx of persons newly insured under the Patient Protection and Affordable Care Act. These programs have been successful in increasing access to health care in rural areas, helping communities create new health programs for those in need and training the future health professionals that will give care to rural America. With modest investments, these programs are able to evaluate, study and implement quality improvement programs and health information technology systems.

While we recognize the constraints of the current fiscal climate, we would like to remind you of the critical importance of these rural health programs and request modest increases to ensure that these programs do not lose ground in a time of a growing patient base. Small investments in these "rural health safety net" programs realize big gains in rural communities. In the long run, the federal government will pay a much higher cost should it walk away from its commitment to monitor and improve health care in rural America.

Some important rural health programs supported by the NRHA are outlined below.

Rural Health Outreach and Network Grants provide capital investment for planning and launching innovative projects in rural communities that later become self-sufficient. These grants are unique in the federal system as they allow the community to choose what is most important for their own situation and then build a program around that. These grants have led to projects dealing with obesity and diabetes, information technology networks, oral screenings, preventive services, and many other health concerns. Due to the community nature

of the grants and a focus on self-sustainability after the terms of the grant have run out - 85 percent of the Outreach Grantees continue to deliver services even five full years after federal funding had ended. **Request: \$58.3 million**

Rural Health Research and Policy forms the federal infrastructure for rural health policy. Without these funds, rural America has no coordinated voice in the Department of Health and Human Services (HHS). In addition to the expertise provided to agencies such as the Centers for Medicare and Medicaid Services, this line item also funds rural health research centers across the country. These research centers provide the knowledge and the evidence needed for good policy making, both in the federal government and across the nation. Additionally, we urge the Subcommittee to include in report language instructions to the Office of Rural Health Policy to direct additional funding to the state rural health associations. The state associations serve to coordinate rural health activities at the state level and have a strong record of positive outcomes. **Request: \$10.5 million**

State Offices of Rural Health are the state counterparts to the federal rural health research and policy efforts, and form the state infrastructure for rural health policy. They assist States in strengthening rural health care delivery systems by maintaining a focal point for rural health within each State and by linking small rural communities with State and Federal resources to develop long term solutions to rural health problems. Without these funds, states would have diminished capacity to administer many of the rural health programs that are so critical to access to care. **Request: \$10.4 million**

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects for Critical Access Hospitals across the country. This funding is essential. CAHs are by definition small hospitals with fewer than twenty-five beds; they do not have the size, volume or the expertise to do the types of quality improvement or information technology activities that they need to do. These grants allow statewide coordination and provide expertise to CAHs. Also funded in this line is the **Small Hospital Improvement Program (SHIP)**, which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to help improve their business operations, focus on quality improvement and to ensure compliance provisions related to health information privacy. **Request: \$42.4 million**

Rural and Community Access to Emergency Devices assists communities in purchasing emergency devices and training potential first responders in their use. Defibrillators double a victim's chance of survival after sudden cardiac arrest, which an estimated 163,221 Americans experience every year. **Request: \$3.4 million**

The **Office for the Advancement of Telehealth** supports distance-provided clinical services and is designed to reduce the isolation of rural providers, foster integrated delivery systems through network development and test a range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, provide constant education to isolated rural providers and save money through reduced office visits and expensive hospital care.

These approaches are still new and unfolding and continued investment in the infrastructure and development is needed. **Request: \$12.0 million**

National Health Service Corps (NHSC) plays a critical role in providing primary health care services to rural underserved populations by placing health care providers in our nation's most underserved communities. Investment in our health care workforce is absolutely vital to support the newly insured population resulting from health reform. Programs like the NHSC help to maximize the capacity of our health system to care for patients. The Patient Protection and Affordable Care Act provided additional funding to the NHSC through the HHS Secretary's Community Health Center fund. The NRHA is supporting the President's request, which will ensure that the NHSC has access to the additional dedicated funding through the CHC Fund. **Request: \$169.0 million**

Title VII Health Professions Training Programs (with a significant rural focus):

- **Rural Physician Pipeline Grants** will help medical colleges to develop special rural training programs and recruit students from rural communities, who are more likely to return to their home regions to practice. Newly created under the Patient Protection and Affordable Care Act, this "grow-your-own" approach is one of the best and most cost-effective ways to ensure a robust rural workforce into the future. **Request: \$4.0 million**
- **Area Health Education and Centers (AHECs)** financially support and encourage those training to become health care professionals to choose to practice in rural areas. Without this experience and support while in medical school, far fewer professionals would make the commitment to rural areas and facilities including Community Health Centers, Rural Health Clinics and rural hospitals. It has been estimated that nearly half of AHECs would shut down without federal funding. The success of this program was recognized through increased authorized levels in the Patient Protection and Affordable Care Act. **Request: \$75.0 million**
- **Geriatric Programs** train health professionals in geriatrics, including funding for Geriatric Education Centers (GEC). There are currently 47 GECs nationwide that ensure access to appropriate and quality health care for seniors. Rural America has a disproportionate share of the elderly and could see a shortage of health providers without this program. **Request: \$34.7 million**

The NRHA appreciates the Subcommittee's strong support in the FY 2010 Omnibus Appropriations bill and the opportunity to provide our recommendations for your fiscal year 2011 appropriations bill. Our request for continued funding for the rural health safety net is critical to the provision of, and access to, high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of Congress to reinvest in rural health in FY 2011 and into the future.

Testimony of Fred Lugo President, National Senior Corps Association

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**Subcommittee on Labor, Health and Human Services, Education and Related Agencies
National Senior Service Corps FY 2011 (Corporation for National and Community Service)**

Mr. Chairman, Members of the Committee, my name is Fred Lugo and I am Director of the Travis County (Texas) RSVP Program. I testify today on behalf of the National Senior Corps Association, representing the interests and ideals of 500,000 senior volunteers and the directors, staff, and friends of local Foster Grandparent, Senior Companion, and RSVP programs throughout the country.

For Fiscal Year 2011, NSCA requests \$132,962,147 for the **Foster Grandparent Program (FGP)**, \$67,589,771 for **RSVP**, and \$59,780,346 for the **Senior Companion Program (SCP)**. This is an aggregate increase of \$39,432,264 over the FY 2010 enacted level. This level of funding will provide for continued support and a small administrative increase for existing grantees, competition for new grantees, and a stipend increase for Foster Grandparents and Senior Companions. Our request is composed of the following goals:

- **Support for Continuing Services - \$220,900,000 (FGP - \$110,996,000; RSVP - \$63,000,000; SCP - \$46,904,000).** These grant funds allow existing Senior Corps programs and the nearly 500,000 volunteers to continue providing critical services, including:
 - ◊ **Independent living services.** SCP volunteers provide companionship and support needed to help frail seniors remain independent and in their own homes at a cost lower than institutional care. RSVP volunteers provide a range of services to frail elders and people with disabilities, and respite to caregivers to help preserve independent living and reduce costly institutionalization.
 - ◊ **Mobilizing volunteers.** RSVP volunteers recruit or manage additional community volunteers to serve in local communities.
 - ◊ **Serving children and vulnerable families.** FGP volunteers tutor children with low literacy skills and mentor troubled teenagers and young mothers. RSVP volunteers tutor thousands of children, and steer disadvantaged children and youth toward a more productive and responsible path.
 - ◊ **Assisting in disaster preparedness and recovery.** Often the first national service participants to respond, RSVP volunteers staff emergency kitchens and shelters, distribute food and clothing, and assist in relocating affected individuals and families.
 - ◊ **Assisting with clean energy programs.** RSVP volunteers provide home-based services such as weatherization and handyman assistance to families in need of extra support.
- **New Initiatives - \$5,940,050 (FGP - \$2,047,550; RSVP - \$1,800,000; SCP - \$2,092,500).** 10 new FGP and 10 new SCP programs will be established in geographic areas that do not currently have existing programs and that address current priorities. 20 new RSVP programs will be established to support the work of nonprofit organizations that address current priorities. Current priorities include child obesity, high school completion, jobs, long-term care, and family caregiver support.
- **Administrative Adjustment - \$4,418,000 (FGP - \$2,219,920; RSVP - \$1,260,000; SCP - \$938,080).** Senior Corps programs will receive a 2% increase to expand organizational capacity and for other essential administrative costs. Support is particularly crucial in the current economic environment.

- **Stipend Increase - \$15,931,440 (FGP - \$10,377,360; SCP - \$5,554,080).** Foster Grandparents and Senior Companions will receive a \$.35 stipend increase from \$2.65/hour to \$3.00/hour. Amount is based on current volunteer levels.
- **Programs of National Significance (PNS) Grants - \$13,142,774 (FGP - \$7,321,317; RSVP - \$1,529,771; SCP - \$4,291,686).** PNS grants expand operations and services into new geographic areas, and increase the number of volunteers. PNS grants are awarded on a competitive basis.
- **Silver Scholarships.** While current legislation does not exclude Senior Corps volunteers from receiving Silver Scholarships, it does not specifically state that they are included. NSCA requests allowing flexibility in rule interpretation to allow Senior Corps program eligibility for Silver Scholarships. Silver Scholarships are \$1,000 transferable education awards for adults age 55 and older who serve 350 hours per year. The award may be given to their child or grandchild. NSCA requests \$1,000,000 for Silver Scholarships.

SENIOR CORPS is a federally authorized and funded network of national service programs that provides older Americans with the opportunity to apply their life experiences to volunteer service. Senior Corps is comprised of the **Foster Grandparent Program, RSVP, and the Senior Companion Program**, through which Americans age 55 and older provide essential services to cost-effectively address critical community needs.

Foster Grandparent Program: 29,000 Foster Grandparents in 328 projects provide a cost-effective means to reach and support more than 280,000 at-risk children with special or exceptional needs annually who otherwise may not have the opportunity to receive individual assistance and attention from a caring adult. In 2009, Foster Grandparents volunteered 24.3 million hours.

- 81% of children served demonstrated improvements in academic performance. Mentored children have reduced truancy resulting in reduced school costs and, ultimately, reduced high school dropout rates and increased lifetime earnings.
- 90% demonstrated increased self-image. This includes improved health outcomes such as reductions in teen pregnancy and reduced or delayed use of tobacco, alcohol, or illicit drugs.
- 56% reported improved school attendance leading to increased graduation rates, increased post-secondary education, and higher lifetime earnings.
- 59% reported reduction in risky behavior, including reduced juvenile violence and property crimes, saving victim and court expenses, costly treatment of juvenile offenders, costs of adult crime, crime losses of victims and the societal costs of prosecuting and incarcerating adult offenders.
- In 2009, FGP volunteers mentored 41,767 children and youth, of which 5,400 were children of prisoners at high risk of repeating their parent's path.
- FGP intervention reduced need for social services, both short-term costs of counseling and long-term costs of public assistance.
- Based on conservative assumptions about outcomes and valuations, studies indicate a return benefit of \$2.72 for every dollar of resources used for mentoring programs. (*Analyzing the Social Return on Investment in Youth Mentoring Programs*, prepared by: Paul A. Anton, Wilder Research; and Prof. Judy Temple, University of Minnesota).

Foster Grandparent Program Profiles: Foster Grandparent Birda Dillon completed the ninth grade, worked doing factory assembly for 25 years, raised more than 20 children - 14 of her own as well as grandchildren. She is a remarkable Foster Grandparent as the following remarks from her teacher in

Benton Harbor, MI begin to illustrate: "Grandma is so good with these students. She knows just how to work with them to get them to read the words themselves. She is positive and knows how to get the students to sound the words out. George is reading so much better. I was surprised when he told me recently, 'I need another book!' I can't spend one-on-one time with them, and she can. Birda is one of the best reading tutors I've encountered in my many years of teaching. She knows all of the tricks and tools to help the students help themselves. She said much of what she knows she has learned through her training as a Foster Grandparent. I appreciate her giftedness very much. We hope we can be together for a long, long time." From Professional Volunteer who assists with site visits (a retired veteran teacher): "I complimented her on her teaching of reading and told her I was a reading teacher, too. I told her she was a natural! She said she hadn't had any formal training; she wished she'd been a teacher, and I told her she was." Three of the children Birda tutors have incarcerated parents.

Foster Grandparent Leila Williams serves in a first grade classroom at Washington Elementary School in Coloma, MI. "I had no idea how rewarding it would be. And I feel so much better. I love having a schedule, being busy, and I sleep so good at night. Thank you, for making my life better. I'm 91 years old, and getting younger." Leila is matched with two children with parents in active military service. Leila's teacher reports that as a result of Leila's one-on-one attention, her two assigned students have developed positive relationships with Leila, improved socialization skills and have both improved reading skills, especially sight word recognition and fluency.

RSVP: 405,000 RSVP volunteers contributed 62 million hours of service in 2009 through 741 projects nationwide working with more than 65,000 community organizations. The average cost to support one RSVP volunteer is approximately \$145 a year, whereas the average annual value per volunteer is more than \$3,000. RSVP volunteers saved local communities \$1.25 billion in 2009.

- RSVP is continually strengthening its leadership role in engaging volunteers 55+ by providing nonprofit agencies with volunteers trained to recruit and coordinate other community members in support of the nonprofits mission and goals. In 2009, RSVP volunteers recruited 38,000 additional community volunteers.
- RSVP projects demonstrate that their volunteer services increase literacy scores for the 74,326 children they mentor – the National Education Association states the lowest hourly rate for teacher aides is \$10.31 reflecting a savings of \$16,858,623 in remedial reading assistance. 24,370 RSVP volunteers increased the capacity of the organizations where they serve by enhancing both the quality and quantity of services.
- In 2009, RSVP volunteers mentored 6,400 children of prisoners at high risk of repeating their parent's path.
- RSVP volunteers provided 23,300 caregivers with respite services. A recent AARP survey of working caregivers reports that 30% of family caregivers either quit their jobs or reduce their work hours to take on more care giving responsibilities.
- RSVP volunteers supported 509,000 with Independent Living Services.
- 30% of RSVP volunteers provided at least one service in the area of Health/Nutrition which includes in-home and congregate meals, food distribution/collection, immunization, etc. valued at more than \$27 million.

RSVP Program Profile: The Beginning Alcohol and Addictions Basic Education Studies (BABES) program has been operating successfully for many years in districts throughout the Portage County, WI RSVP service area. Each year, hundreds of second graders in the various districts learn from their puppet friends (via the RSVP volunteers) about complex issues like peer pressure, good decision making, and asking for help.

In 2009, over 600 second graders participated in the program. The intermediate outcome states that teachers in the second grade classes will observe children using phrases from the presentations and reminding others about the lessons they have learned. In 2009, the target was exceeded as 21 teachers returned surveys and 90% (19) reported they observed children using phrases from the BABES presentations. Teacher comments included: 1) "They have brought up coping, decision making, peer pressure and self image when we are reading other stories. They have made a connection from these lessons to what is going on in their world." 2) "One student came in from recess and said someone was peer pressuring her to do something on the playground. It was great hearing the term used!"

The end outcome states that students in second grade classes who complete the BABES program will show an increase in knowledge about alcohol and drug use and abuse and seeking help as measured on a pre/post test. In 2009, the target was exceeded as 74% (20 of 27 classes participating in BABES in 2009) of classes improved their scores on the post test by at least 10%.

While the program is successful because volunteers are willing to present the lessons, the coordination of the program is also an important piece. The RSVP Intergenerational Coordinator provides annual volunteer training, ensures volunteers have all the materials they need, works with the schools to schedule the program, ensures the pre and post tests are completed and returned and analyzes and reports the data collected to all the stakeholders.

Senior Companion Program: 15,200 Senior Companions serving in 194 projects provided 12.2 million hours of service helping 68,200 frail, homebound clients in need of assistance in order to remain living independently. Senior Companion Program services prevented premature and costly institutionalization at an annual savings well over \$200 million. The national average cost for one year in a nursing home is \$72,270; the assisted living facility yearly average cost is \$37,572. One Senior Companion volunteer assists 2-6 homebound clients for the annual investment of \$4,800.

- Senior Companions offered essential respite to nearly 9,000 primary caregivers who struggle to remain in the regular workforce while caring for their loved one.
- The Family Caregiver Alliance reports that families with long-term care responsibilities miss an average of 7.5 workdays each year.
- The MetLife Caregiving Cost Study of July 2006 reports the estimated cost to employers of full-time employed intense caregivers at a total of \$17.1 billion in lost productivity annually as well as absenteeism, workday interruptions, costs due to crisis in care, supervision costs associated with caregiver employees, costs with unpaid leave and reducing hours from full-time to part-time.
- Clients have significant, long-term mental health benefits and reduced rates of depression saving \$50 - \$75 a month in medication.
- Cost of stress management therapy for one caregiver (\$125 per session) vs. respite provided by volunteer (4 hours of respite care = \$10.60 plus mileage average cost of \$3).

- Cost for a home health aide after a client's release from the hospital is \$21 per hour as compared to \$2.65 per hour for a Senior Companion volunteer (at no cost to clients).

Senior Companion Program Profile: Julia, an 80-year old woman who is blind was faced with having to leave her home in Rochester, NY due to her inability to see and complete the tasks of daily living needed to stay independent. While she had home health aide service to help her bathe, dress and clean her apartment, her family wasn't able to be with her during the day and evening due to their work schedules and their own family commitments.

Julia was given two Senior Companion (SC) volunteers. One came each day mid-morning after the home health aide left and stayed until early afternoon. The SC kept Julia company, escorted her to the bathroom when needed, fixed lunch and ensured she was okay daily. The 2nd SC came about 5pm each evening. She fixed dinner, visited, cleaned up after dinner and helped Julia get ready and into bed each evening.

Between these two volunteers Julia was able to stay living at home an additional 5+ years. At an average cost of \$70,000 annually for long term care compared to the cost of her SC services at approximately \$4,800 annually per companion, a savings of over \$300,000 was saved.

It has been stated that baby boomer and senior volunteers represent our Nation's single and fastest growing resource. During this unprecedented economic crisis facing our Nation, the number of baby boomer and senior volunteers should be greatly expanded and mobilized as solutions to the problems facing our local communities. NSCA's 2011 budget request will provide the opportunity for thousands more older adults to serve in their communities and enhance the lives of those most in need, including children with special needs, the frail and isolated elderly striving to maintain independence, and expanding the services of local non-profit agencies.

**The 2009 national value of one hour of volunteer service was estimated at \$20.25
Senior Corps volunteers' 98.2 million service hours in 2009 = \$1.99 billion savings**

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TESTIMONY TO

**HOUSE SUBCOMMITTEE ON LABOR, HEALTH & HUMAN
SERVICES, EDUCATION AND RELATED AGENCIES**

SUBMITTED BY

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REGARDING

**FISCAL YEAR 2011 FUNDING FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES**

April 15, 2010

SUMMARY OF FY 2011 RECOMMENDATIONS

- Provide \$2 million in funding for sleep activities within the Community Health Promotion account within the Chronic Disease Program at the Centers for Disease Control and Prevention (CDC). Expanded funding for sleep and sleep disorder-related activities would allow the CDC fund additional states to collect essential national and state-specific surveillance data; to support targeted public awareness initiatives; to create training materials for health care professionals; and build and test public health interventions.

Mr. Chairman and members of the Subcommittee, thank you for allowing me to submit testimony on behalf of the National Sleep Foundation (NSF). I am Dr. Frankie Roman, Chair of the NSF's Government Affairs Committee and a sleep specialist at Ohio Sleep Disorder Centers, in Akron, Ohio. NSF is an independent, non-profit organization that is dedicated to improving public health and safety by achieving understanding of sleep and sleep disorders, and by supporting sleep-related education, research and advocacy. We work with sleep medicine and other health care professionals, researchers, patients and drowsy driving advocates throughout the country as well as collaborate with many government, public and professional organizations with the goal of preventing health and safety problems related to sleep deprivation and untreated sleep disorders.

Sleep problems, whether in the form of medical disorders or related to work schedules and a 24/7 lifestyle, are ubiquitous in our society. It is estimated that sleep-related problems affect 50 to 70 million Americans of all ages and socioeconomic classes. Sleep disorders are common in both men and women; however, important disparities in prevalence and severity of certain sleep disorders have been identified in minorities and underserved populations. Despite the high prevalence of sleep disorders, the overwhelming majority of sufferers remain undiagnosed and untreated, creating unnecessary public health and safety problems, as well as increased health care expenses. Annual surveys conducted by NSF show that more than 60 percent of adults have never been asked about the quality of their sleep by a physician, and fewer than 20 percent – have ever initiated such a discussion.

Additionally, Americans are chronically sleep deprived as a result of demanding lifestyles and a lack of education about the impact of sleep loss. Sleepiness affects vigilance, reaction times, learning abilities, alertness, mood, hand-eye coordination, and the accuracy of short-term memory. Sleepiness has been identified as the cause of a growing number of on-the-job accidents, automobile crashes and multi-modal transportation tragedies.

According to the National Highway Traffic Safety Administration's *2002 National Survey of Distracted and Drowsy Driving Attitudes and Behaviors*, an estimated 1.35 million drivers have been involved in a drowsy driving crash in the previous five years. According to NSF's 2009 *Sleep in America* poll, 54% of people admit that they have driven drowsy at least once in the past year, with 28% reporting that they do so at least once a month or more! A large number of academic studies and government reports have linked lost productivity, poor school performance, and major public health problems to chronic sleep loss and sleep disorders.

The 2006 Institute of Medicine (IOM) report, *Sleep Disorders and Sleep Deprivation: An Unmet Public Health Problem*, found the cumulative effects of sleep loss and sleep disorders represent an under-recognized public health problem and have been associated with a wide range of negative health consequences, including hypertension, diabetes, depression, heart attack, stroke, and at-risk behaviors such as alcohol and drug abuse – all of which represent long-term targets of the Department of Health and Human Services (HHS) and other public health agencies. Moreover, the personal and national economic impact is staggering. The IOM estimates that the direct and indirect costs associated with sleep disorders and sleep deprivation total hundreds of billions of dollars annually.

Sleep science and federal reports have clearly detailed the importance of sleep to health, safety, productivity and well-being, yet studies continue to show that millions of Americans remain at risk for serious health and safety consequences of untreated sleep disorders and inadequate sleep, due to a lack of awareness, community interventions, and inadequate screening. Unfortunately, despite recommendations in numerous federal reports, there is a lack of epidemiological data, large clinical trials and no on-going national educational programs regarding sleep issues aimed at the general public, health care professionals, underserved communities or major at-risk groups.

NSF believes that every American needs to understand that good health includes healthy sleep, just as it includes regular exercise and balanced nutrition. Sleep must be elevated to the top of the national health agenda in order to adequately address other national public health problems mentioned above. We need your help to make this happen.

Our biggest challenge is bridging the gap between the established sleep science best practices and the level of knowledge about sleep held by health care practitioners, educators, employers, and the general public. Because resources are limited and the challenges great, we think creative and new partnerships are needed to fully develop sleep awareness, education and clinical training initiatives. Consequently, the NSF has spearheaded important initiatives to raise awareness of the importance of sleep to the health, safety and well-being of the nation. One of our most important partnerships in these efforts is with the Centers for Disease Control and Prevention.

For the last seven years, Congress has recommended that the CDC support activities related to sleep and sleep disorders. As a result, CDC's National Center for Chronic Disease Prevention and Health Promotion has been collaborating with NSF and more than twenty voluntary organizations and federal agencies to form the National Sleep Awareness Roundtable (NSART), which was officially launched in March of 2007. Congress also provided specific funding for these efforts for the past three years.

In FY 2008, Congress provided \$818,000 for activities related to sleep and sleep disorders, including CDC's participation in NSART and incorporating sleep-related questions into established CDC surveillance systems. With this funding, CDC included one core sleep question in its national data collection efforts in 2008 and has provided grants to 8 states to include an optional sleep module in their data collection efforts through the Behavioral Risk Factor Surveillance System (BRFSS). Recent analysis of the core data found that over 1 in 10 Americans report having insufficient sleep or rest every day for the past 30 days. Significantly, sleep problems were found to be more prevalent in southeastern states in what is commonly referred to as the "stroke belt." This region has an unusually high incidence of stroke, cardiovascular disease, diabetes, obesity, depression, and quality of life, which are associated with inadequate sleep quality and quantity. The CDC is currently recruiting up to 14 states and hopes to expand the data collection to all 50 states if appropriate funding is obtained.

CDC also included one question in the Youth Risk Behavior Surveillance System (YRBSS). Of note, the YRBSS has already revealed that only one-third of high-school students get 8 or more hours of sleep on an average school night, far below the recommended 9.25 hours. This new data will provide important information on the prevalence of sleep disorders and enable researchers to

better address the complex interrelationship between sleep loss and comorbid conditions such as obesity, diabetes, depression, hypertension, and drug and alcohol abuse.

Additionally, CDC and NSART supported and actively participated in NSF's ongoing national public awareness initiatives including National Sleep Awareness Week and Drowsy Driving Prevention Week. The year, with CDC's support and guidance, NSF launched a new initiative called Sleep Health and Safety Conference 2010 designed to educate clinicians and other health care professionals about sleep disorders in order to increase better diagnosis and treatment.

In FY 2009, Congress provided \$900,000 to the CDC for sleep activities. CDC plans to expand the number of states it is able to fund for BRFSS data collection and provide support for national public and professional awareness initiatives as well as activities of the National Sleep Awareness Roundtable.

Although the CDC has taken initial steps to begin to consider how sleep affects public health issues, the agency needs additional resources to take appropriate actions, as recommended by the IOM and other governmental reports. Expanded funding for sleep and sleep disorder-related activities would allow the CDC to create much needed educational programs for schools and occupational settings and training materials for current and future health professionals; build and test public health interventions; expand surveillance and epidemiological activities; and create further fellowships and research opportunities. The following are detailed scenarios for various funding levels.

- **\$2 million:**
 - **Expand Surveillance on BRFSS.** CDC could double the number of grants it provides to states to use the optional sleep module and include more core questions in the nationwide data collection through the Behavioral Risk Factor Surveillance System. CDC would also expand its participation in and funding of national public and professional initiatives aimed at promoting sleep as a health behavior, treatment of obstructive sleep apnea, and drowsy driving as well as the goals and activities of the National Sleep Awareness Roundtable.
 - **Public Education.** CDC could support the development of a national sleep health communications campaign that use targeted approaches for delivering sleep-related messages, especially in public schools and workplaces. Currently, no such programs exist.

NSF and members of the National Sleep Awareness Roundtable believe that an ongoing partnership with CDC is critical to address the enormous public health impact of sleep and sleep disorders. We hope that the Committee will provide funding of \$2,000,000 to the CDC to execute programs as outlined here.

Thank you again for the opportunity to present you with this testimony.

National Technical Institute for the Deaf (NTID), Rochester Institute of Technology (RIT)
U.S. Department of Education
Submitted by: Dr. James J. DeCaro
Interim President, NTID
Interim Vice President and Dean, RIT
Email: JJD80774@rit.edu Phone: (585) 475-5978

Mr. Chairman and Members of the Committee:

I am pleased to present the FY 2011 budget request for NTID, one of eight colleges of RIT, in Rochester NY. Created by Congress (Public Law 89-36) in 1965, we provide university technical and professional education for students who are deaf and hard-of-hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. We also provide baccalaureate and graduate level education for hearing students in professions serving individuals who are deaf and hard-of-hearing. As of fall 2009, NTID served a total 1,474 students from across the nation, including 1,307 deaf and hard-of-hearing students and 167 hearing students. NTID students live, study and socialize with more than 15,000 hearing students on the RIT campus.

NTID has fulfilled our mission with distinction for 42 years.

BUDGET REQUEST:

As shown below, NTID's FY 2011 Budget Request was \$66,252,000 in Operations and \$3,640,000 in Construction, for a total of \$69,892,000; the President's Request is \$63,037,000 in Operations and \$1,640,000 in Construction, for a total of \$64,677,000.

FY2011 Budget Request Status

| | Operations | Construction | Total |
|-----------------------------|--------------------|---------------------|--------------------|
| NTID Request | \$66,252,000 | \$3,640,000 | \$69,892,000 |
| President's Request* | \$63,037,000 | \$1,640,000 | \$64,677,000 |
| Difference | \$3,215,000 | \$2,000,000 | \$5,215,000 |

For the last two fiscal years (2009 and 2010), NTID's Operations budget has been funded at the same level of \$63,037,000; the President's recommended budget for FY 2011 would mark a third consecutive year of funding at this level.

For these past two years, NTID has been able to absorb level-funding in Operations primarily due to two factors: (1) a self-initiated budget-reduction/revenue enhancement campaign from FY 2003 through FY 2007; and (2) a withholding of salary increased by RIT for FY 2010. However, realized savings from the campaign now have been re-allocated and are no longer available, and RIT recently has announced a 2.0% salary increase for FY 2011.

While NTID certainly would benefit from a budget increase to support upcoming strategic initiatives (see below), we understand the resource challenges facing the Committee this year. While an additional \$1,640,000 beyond the President's recommended Operations funding for FY 2011 is needed, **we are amenable to meeting this need by shifting funds designated in the President's 2011 budget from Construction to Operations. This would ensure NTID stays within the total allocation proposed in the President's 2011 budget of \$64,677,000, and still fully meet our Operations needs.** We will seek alternative funding for needed construction items.

ENROLLMENT:

In FY 2010 (Fall 2009), we attracted the largest enrollment in our 42-year history. Truly a national program, NTID enrolls students from all 50 states. Our current enrollment is 1,474. Over the last three years our enrollment has increased 18% (224 students). For FY 2011, NTID anticipates maintaining this record high enrollment level. Our enrollment history over the last five years is shown below:

NTID Enrollments: Five-Year History

| Fiscal Year | Deaf/Hard-of-Hearing Students | | | | Hearing Students | | | Grand Total |
|-------------|-------------------------------|----------|------|-----------|----------------------|------|-----------|-------------|
| | Undergrad | Grad RIT | MSSE | Sub-Total | Interpreting Program | MSSE | Sub-Total | |
| 2006 | 1,013 | 53 | 38 | 1,104 | 116 | 36 | 152 | 1,256 |
| 2007 | 1,017 | 47 | 31 | 1,095 | 130 | 25 | 155 | 1,250 |
| 2008 | 1,103 | 51 | 31 | 1,185 | 130 | 28 | 158 | 1,343 |
| 2009 | 1,212 | 48 | 24 | 1,284 | 135 | 31 | 166 | 1,450 |
| 2010 | 1,237 | 38 | 32 | 1,307 | 138 | 29 | 167 | 1,474 |

STUDENT ACCOMPLISHMENTS:

For our graduates, 95% have been placed in jobs commensurate with the level of their education (using the Bureau of Labor Statistics methodology). Of our FY 2007 graduates (the most recent class for which numbers are available), 63% were employed in business and industry, 29% in education/non-profits, and 8% in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a noteworthy reduction in dependence on Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and public assistance programs. In FY 2007, NTID, the Social Security Administration, and Cornell University examined approximately 13,000 deaf and hard-of-hearing individuals who applied and attended NTID over our entire history. We learned that graduating from NTID has significant economic benefits. By age 50, deaf and hard-of-hearing baccalaureate graduates earned on average \$6,021 more per year than those with associate degrees, who in turn earned \$3,996 more per year on average than those who withdrew before graduation. Students who withdrew earned \$4,329 more than those who were not

admitted. Students who withdrew experienced twice the rate of unemployment as graduates.

The same studies showed 78% of these individuals were receiving SSI benefits at age 19, but when they were 50 years old, only 1% of graduates drew these benefits, while on average 19% of individuals who withdrew or were not admitted continued to participate in the SSI program. Graduates also accessed SSDI, an unemployment benefit, at far lesser rates than students who withdrew; by age 50, 34% of non-graduates were receiving SSDI, while 22% of baccalaureate graduates and 27% of associate graduates were receiving them. Considering the reduced dependency on these federal income support programs, the federal investment in NTID returns significant societal dividends.

NTID clearly makes a substantially positive difference in earnings, and in lives.

STRATEGIC INITIATIVES BEGINNING FY2011:

NTID has just completed *Strategic Decisions 2020*, a strategic plan based on our founding mission statement. This statement sets forth our institutional responsibility to work with students to develop their academic, career and life-long learning skills as future contributors in a rapidly changing world. It also recognizes our role as a special resource for preparing individuals for professions serving individuals who are deaf and hard-of-hearing, for conducting applied research in areas critical to the advancement of individuals who are deaf and hard-hard-of hearing, and for disseminating our collective and cumulative expertise.

Strategic Decisions 2020 establishes key initiatives responding to future challenges and shaping future opportunities. These initiatives, scheduled for implementation beginning in FY 2011, include:

- Pursuing enrollment targets and admissions and programming strategies that will result in increasing numbers of our graduates achieving baccalaureate degrees and higher, while maintaining focus and commitment to quality associate-level degree programs leading directly to the workplace;
- Improving services to under-prepared students through working with regional partners to implement intensive summer academic preparation programs in selected high-growth, ethnically diverse areas of the country. Through this initiative, NTID will identify those students demonstrating promise for success in career-focused degree-level programs and beyond, and provide consultation to others regarding postsecondary educational alternatives;
- Expanding NTID's role as a National Resource Center of Excellence regarding the education of deaf and hard-of-hearing students in senior high school (grades 10, 11 and 12) and at the postsecondary level education. Components of this role as a National Resource Center of Excellence will include:

- **Center for Excellence in STEM Education** NTID currently is working to develop an externally funded Center of Excellence on STEM Education for Deaf and Hard of Hearing Students. This is an example of making our expertise available nationally and enhancing deaf and hard-of-hearing students' access to STEM fields.
- **NTID Research Centers** NTID will organize research resources into Research Centers focused on the following strategic areas of research: Teaching and Learning; Communication; Technology, Access, and Support Services; and Employment and Adaptability to Social Changes and the Global Workplace.
- **Outreach Programs** Extending outreach activities to junior and senior high school students who are deaf and hard-of-hearing, many of who represent AALANA populations, to expand their horizons regarding a college education. We also support other colleges and universities serving students who are deaf and hard-of-hearing, as well as post-college adults who are deaf and hard-of-hearing.
- Enhancing efforts to become a recognized national leader in exploring, adapting, testing, and implementing new technologies to enhance access to, and support of, learning by deaf and hard-of-hearing individuals.

NTID BACKGROUND:

Academic Programs

NTID offers high quality career-focused associate degree programs preparing students for specific well-paying technical careers. A cooperative education component ties closely to high demand employment opportunities. NTID also is expanding the number of its transfer associate degree programs, currently numbering seven, to better serve the higher achieving segment of our student population seeking bachelors and masters degrees in an increasingly demanding marketplace. These transfer programs provide seamless transition to baccalaureate studies in the other colleges of RIT. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including interpreting, real-time speech-to-text captioning, and note-taking) as well as tutoring services. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students to gain admission to, and graduate from, the other colleges of RIT at rates comparable to their hearing peers.

Student Life

Our activities foster student leadership and community service, and provide opportunities to explore a wide range of other educational interests. Emphasis is placed on coordination between academic faculty and student development professionals in supporting college success for students.

SUMMARY:

It is extremely important that our funding be provided at the full level requested by the President as we continue our mission to prepare deaf and hard-of-hearing people to enter the workplace and society. **We ask only that the funds provided by the President for Construction be moved into Operations.**

Our alumni have demonstrated that they can achieve independence, contribute to society, earn a living, and live a satisfying life as a result of NTID. Research shows that NTID graduates over their lifetimes are employed at a much higher rates, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in SSI, SSDI, and public assistance programs than those who withdraw or who apply but do not attend NTID.

We are hopeful that the members of the Committee will agree that NTID, with its long history of successful stewardship of federal funds and outstanding educational record of service with people who are deaf and hard-of-hearing, remains deserving of your support and confidence.

Kevin Coyle
Vice President for Education and Training
National Wildlife Federation
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Testimony on the University Sustainability Program (USP), Energy Conservation Corps, Environmental Education at the Department of Education, Education and Training for Clean Energy and “Green” Jobs, and Related Programs

For the
Subcommittee on Labor, Health and Human Service, Education and Related Agencies
Committee on Appropriations
U.S. House of Representatives

Mr. Chairman, Members of the Subcommittee, on behalf of the National Wildlife Federation (NWF), our nation’s largest conservation advocacy and education organization, and our more than four million members and supporters, I thank you for the opportunity to provide funding recommendations for the Department of Education, Department of Labor (DOL), and the Corporation for National and Community Service (CNCS).

We believe that the overall federal investment in environmental and sustainability education programs nationwide – pennies per capita – is woefully inadequate. While NWF supports numerous programs under the jurisdiction of this Subcommittee, the purpose of this testimony is to recommend levels of funding for specific sustainability education at institutions of higher education, education and training for clean energy and “green” jobs, environmental education at the K-12 level, and national service programs that we believe are vital to NWF’s mission to inspire Americans to protect wildlife for our children’s future. The National Wildlife Federation also supports climate change education and environmental education programs across the federal agencies at the U.S. Forest Service, Environmental Protection Agency, National Science Foundation, National Space and Atmospheric Administration, National Oceanic and Atmospheric Administration, and U.S. Department of the Interior.

Summary of Recommendations:

| Agency | Program | FY 2011 Recommendation | FY 2010 Level |
|------------------|-----------------------------------|-------------------------------|---------------------------|
| Education | University Sustainability Program | \$50 million | \$0 million* (see page 3) |
| Education | Healthy High Performance Schools | \$25 million | \$0 million |
| Labor | Green Jobs Act | \$125 million | \$50 million |
| CNCS | Clean Energy Service Corps | \$100 million | \$0 million |

Funding for these programs is supported broadly through the Campaign for Environmental Literacy’s *Green Education Budget* and the conservation community’s *Green Budget* documents.

The Need for Environmental Education and Sustainability Education

As our nation moves towards a clean energy economy and creates new “green jobs,” we must ensure that our education and training infrastructure keeps pace. Congress and President Obama have stated their desire to pass comprehensive climate change legislation this year, a priority that the National Wildlife Federation strongly supports. To be successful and remain competitive as a nation in a new clean energy economy, we must have an environmentally literate and well-trained citizenry that has the knowledge and skills to find new and innovative solutions to protect our planet. While public awareness and concern about global warming continues to rise, the vast majority of the public does not understand how climate change works, how it impacts their lives and careers, and how their decisions and actions contribute to it. Consider the following examples:

- Survey research shows that most Americans do not know what the carbon cycle is or understand what actually causes global warming. They do not know how most electricity is generated or the importance of healthy forests and oceans in generating oxygen and absorbing carbon dioxide.
- Less than half of the population recognizes that the cars and appliances they use contribute to global warming, and eight out of 10 parents admit that they know “little” to “nothing” about the specific causes of climate change.
- The average high school student fails a quiz on the causes and consequences of climate change (nearly 82 percent of participants affirmed, incorrectly, that “scientists believe radiation from nuclear power plants cause global temperatures to rise.”).
- In addition, most students don’t see themselves at risk: Only 28 percent believe it’s very likely that climate change will affect them personally in their lifetimes.

Educating Americans about climate change is a huge opportunity for our nation to prepare today’s leaders, and the leaders of tomorrow, to implement the solutions created through comprehensive climate change legislation. Unfortunately, some still mistakenly see environmental protection programs as a costly burden on prosperity. In fact, the challenge posed is an entrepreneur’s dream. Addressing global warming will generate millions of good new jobs and put the U.S. at the exciting forefront of a new clean energy economy. The successful transition to this new green economy hinges on education and training. This testimony focuses on key programs that educate and train Americans at institutions of higher education, in our nation’s K-12 schools, through conservation corps programs that educate and train at-risk youth for careers in clean energy, and through green workforce education and training programs at the Department of Labor.

Department of Education:

University Sustainability Program

The National Wildlife Federation supports funding the University Sustainability Program (USP) at \$50 million in FY 2011. Interest in sustainability is exploding on college campuses across the nation, and institutions are making remarkable changes to try to reduce campus carbon footprints and energy use. However, despite increasing interest and demand from students, sustainability education programs on college campuses are on the decline according

to a comprehensive study released in August 2008 by the National Wildlife Federation and Princeton Survey Research Associates International, called the "Campus Environment 2008: A National Report Card on Sustainability in Higher Education." Environmental curriculum requirements are slipping and today's students may be less environmentally literate when they graduate than their predecessors.

Congress authorized a new University Sustainability Program (USP) at the Department of Education as Part U of the Higher Education Opportunity Act of 2008 (H.R. 4137). This program has the potential for high impact, high visibility, broad support within higher education, and is responsive to an important national trend in higher education. Sustainability on college campuses is critical, from education in the classroom to facility operations. Higher education produces almost all of the nation's leaders in all sectors and endeavors, and many college campuses are virtually small cities in their size, environmental impact, and financial influence. Campuses use vast amounts of energy to heat, cool, and light their facilities. In all, the nation's 4,100 campuses educate or employ around 20 million individuals and generate over three percent of the nation's GDP. The economic clout of these schools is further multiplied by the hundreds of thousands of business suppliers, property owners, and other commercial and nonprofit entities involved with higher education. Funding for the newly authorized USP is critical to help provide difficult-to-get seed funding to launch sustainability education programs and to help support mainstream higher education associations in including sustainability in their work with their member institutions.

In FY 10 Congress appropriated \$28.8 million for the University Sustainability Program and five other programs as "invitational priorities" under the Fund for Improvement in Postsecondary Education. We recommend that in FY 2011 Congress fund the University Sustainability Program as a standalone program at \$50.0 million.

Healthy High Performance Schools Program

The National Wildlife Federation supports funding the Healthy High Performance Schools Program at \$25 million in FY 2011. The Healthy High Performance Schools Program seeks to facilitate the design, construction and operation of high performance schools: environments that are not only energy and resource efficient, but also healthy, comfortable, well lit, and containing the amenities for a quality education. This grant program is critical at a time when energy costs for America's elementary and secondary schools are skyrocketing. The No Child Left Behind Act (PL 107-110, Title 5, Part D, Subtitle 18) authorized grants to state education agencies to advance the development of "healthy, high performance" school buildings. States may use the funds to provide information, technical assistance, monitor, evaluate, and provide funding to local education agencies for healthy, high performance school buildings. In turn, local agencies may use the funding to obtain technical assistance, develop plans that address reducing energy and meet health and safety codes, and conduct energy audits. Funds may not be used for construction, maintenance, repair or renovation of buildings. This program has yet to be funded by Congress. While it would seem to be a given that we are providing our children with a healthy learning environment, many of the nation's 150,000 public school buildings fall far short of this standard. Research clearly shows that improving specific factors such as school indoor environmental quality improves attendance, academic performance, and productivity.

Pre-K-12 Environmental Education – No Child Left Inside Act

While not yet authorized, the National Wildlife Federation strongly supports authorization of and full funding at \$100 million per year for the No Child Left Inside (NCLI) Act (H.R. 2054), which the support of more than 1,600 national, state and local organizations representing more than 45 million Americans. The central new policy in this legislation is the incentive for states to create or update a State Environmental Literacy Plan. Environmental Literacy Plans can be developed to meet the needs of each state and systemically advance environmental education through the pre-k-12 education system. These state plans in NCLI support training and professional development opportunities for teachers and capacity building for environmental education at both the state and district level. In the past 12 years, an impressive base of research has been developed that demonstrates the positive effects that environmental and nature education programs have on improving academic performance and overall student learning. These data, collected from many peer-reviewed sources, include: improved statewide test results, higher scores in science and mathematics, higher student interest in science, greater real-world relevancy, fewer discipline problems in the classroom, and a more even playing field for students in under-resourced schools.

The House passed a modified version of the bill in the 110th Congress by a bipartisan vote of 293-109. This strong support continues today with 90 current sponsors of H.R. 2054. Additionally, the Department of Education's *A Blue Print for Reform: The Reauthorization of the Elementary and Secondary Education Act* seeks to encourage schools to provide a well-rounded education through grants that support strengthening teaching and learning in environmental education. The Education and Labor Committee's website highlighted the No Child Left Inside Act as one of four key pieces of legislation pending before the Committee for consideration as part of ESEA reauthorization. Thus, it is widely recognized how including environmental education in pre-k-12 systems enhances college and career readiness among students, particularly those of high-need or in low performing schools. In FY 2011, "environmental education" was also included in the President's budget request under a "Well-Rounded Education."

The National Wildlife Federation also supports a priority for funding green career and technical education programs and initiatives at the Department of Education.

Department of Labor:

The National Wildlife Federation supports a priority for green jobs education and training at the Department of Labor through the Workforce Investment Act's Energy Efficiency and Renewable Energy Worker Training Program and the Community Based Job Training Program. NWF believes that community colleges are critical partners in training and educating the next generation of Americans for green jobs.

Energy Efficiency and Renewable Energy Worker Training Program

The National Wildlife Federation supports funding the Energy Efficiency and Renewable Energy Worker Training Program at \$125 million in FY 2011. NWF greatly appreciates this Subcommittee's first-time investment in Green Jobs Education and Training in the recent American Recovery and Reinvestment Act and the \$50 million provided in FY 2010. This unprecedented investment will help jumpstart the education and training needed to prepare Americans for the clean energy economy. We hope that the Committee will continue to fund this program, authorized by the Green Jobs Act (GJA), Title X of the Energy Independence and Security Act, at \$125 million in FY 2011. NWF believes it is important to make annual investments in this program through the regular appropriations process, in addition to necessary infusions of funding through stimulus and supplemental bills. This program identifies needed skills, develops training programs, and trains workers for jobs in a range of green industries, but has a special focus on creating "green pathways out of poverty" and responds to already existing skill shortages. The National Renewable Energy Lab has identified a shortage of skills and training as a leading barrier to renewable energy and energy efficiency growth. This labor shortage is only likely to get more severe as baby-boomers skilled in current energy technologies retire; in the power sector, for example, nearly one-quarter of the current workforce will be eligible for retirement in the next five to seven years.

Corporation for National and Community Service:

Clean Energy Service Corps

The National Wildlife Federation supports funding the Clean Energy Service Corps at \$100 million in FY 2011. The Clean Energy Service Corps, building on the legacy of the depression-era Civilian Conservation Corps and modeled after today's Service and Conservation Corps, will address the nation's energy and environmental needs while providing work and service opportunities, especially for disadvantaged youth ages 16-25. In a manner similar to the Civilian Conservation Corps of the 1930s, disconnected young people may be mobilized through this program to retrofit, weatherize, and otherwise improve the energy efficiency of residential and public facilities that account for more than 40 percent of carbon emissions. Specific projects that are authorized include weatherizing and retrofitting housing units for low-income households, cleaning and improving rivers, and working with schools and youth programs to educate students and youth about ways to reduce home energy use and improve the environment.

Conclusion

Providing federal support for environmental education, sustainability education, green jobs education and training and green national service programs is critical for securing our new clean energy future and preparing the next generation for the challenges and opportunities ahead. Thank you again for providing the National Wildlife Federation with the opportunity to provide testimony.

**AMBASSADORS**

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**FISCAL YEAR 2011 APPROPRIATIONS FOR THE
NATIONAL INSTITUTES OF HEALTH**

**SUBMITTED TO THE
HOUSE COMMITTEE ON APPROPRIATIONS;
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES**

APRIL 16, 2010

SUMMARY OF RECOMMENDATIONS FOR FY10:

- 1) PROVIDE A FUNDING LEVEL OF \$35 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AND A CORRESPONDING INCREASE TO THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK).**
- 2) CONTINUE TO SUPPORT THE *NEPHROTIC SYNDROME RARE DISEASE CLINICAL RESEARCH NETWORK* AT THE OFFICE OF RARE DISEASES RESEARCH (ORDR) INCLUDING COLLABORATION WITH THE NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES.**
- 3) SUPPORT CONTINUED EXPANSION OF THE FSGS/NS RESEARCH PORTFOLIO AT NIDDK BY FUNDING MORE RESEARCH PROPOSALS GENERATED BY THE RECENT PROGRAM ANNOUNCEMENT *GRANTS FOR BASIC RESEARCH IN GLOMERULAR DISEASE (R01)* (PA-10-113).**
- 4) SUPPORT FOR AWARENESS ACTIVITIES THROUGH THE CENTERS FOR DISEASE CONTROL AND PREVENTION CHRONIC KIDNEY DISEASE PROGRAM.**

One Family's Story

Chairman Obey and members of the Subcommittee thank you for the opportunity to provide written testimony today, I am Dee Ryan and my husband is Lieutenant Colonel John Kevin Ryan, an Iraq war veteran. I would like to tell you about my 6 year old daughter Jenna's nephrotic syndrome (NS), a medical problem caused by rare diseases of the kidney filter. When affected, these filters leak protein from the blood into the urine and often cause kidney failure requiring dialysis or kidney transplantation. We have been told by our physician that Jenna has one of two filter diseases called Minimal Change Disease (MCD) or Focal and Segmental Glomerulosclerosis (FSGS). According to a Harvard University report there are presently 73,000 people in the United States who have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are very poorly understood.

In October of 2007 my daughter began to experience general swelling of her body and intermittent abdominal pain, fatigue and general malaise. Jenna began to develop a cough and her stomach became dramatically distended. We rushed Jenna to the emergency room where her breathing became more and more labored and her pulse raced. She had symptoms of pulmonary edema, tachycardia, hypertension, and pneumonia. Her lab results showed a large amount of protein in the urine and a low concentration of the blood protein albumin, consistent with the diagnosis of FSGS. Jenna's condition did not begin to stabilize for several frightening days.

Following her release from the hospital we had to place Jenna on a strict diet which limited her consumption of sodium to no more than 1,000 mg per day. Additionally, Jenna was placed on a steroid regimen for the next three months. We were instructed to monitor her urine protein levels and to watch for swelling and signs of infection, in order to avoid common complications such as overwhelming infection or blood clots. Because of her disease and its treatment, which requires strong suppression of the immune system, Jenna did have a serious bacterial infection several months after she began treatment.

We are frightened by her doctor's warnings that NS and its treatment are associated with growth retardation and other medical complications including heart disease. As a result of NS, Jenna has developed hypercholesterolemia and we worry about the effects the steroids may have on her bones and development. This is a lot for a little girl in kindergarten to endure.

Jenna's prognosis is currently unknown because NS can reoccur. Even more concerning to us is that Jenna may eventually lose her kidneys entirely and need dialysis or a kidney transplant. While kidney transplantation might sound like a cure, in the case of FSGS, the disease commonly reappears after transplantation. And even with a transplant, end stage renal disease caused by FSGS dramatically shortens one's life span.

The NephCure Foundation has been very helpful to my family. They have provided us with educational information about NS, Minimal Change Disease, and FSGS and the organization works to provide grant funding to scientists for research into the cause and cure of NS.

Mr. Chairman, because the causes of Nephrotic Syndrome are poorly understood, and because we have a great deal to learn in order to be able to effectively treat NS, I am asking you to please significantly increase funding for the National Institutes of Health. Also, please support the establishment of a collaborative research network that would allow scientists to create a patient registry and biobank for NS/FSGS, and that would allow coordinated studies of these deadly diseases for the first time. Finally, please urge the National Institute of Diabetes and Digestive and Kidney Disease to continue to focus on FSGS/NS research in general, consistent with the recent program announcement entitled *Grants for Basic Research in Glomerular Disease (R01)* (PA-10-113).

Mr. Chairman, on behalf of the thousands of people suffering from NS and FSGS and the NephCure Foundation, thank you for this opportunity to submit this testimony to the Subcommittee and for your consideration of my request.

More Research is Needed

We are no closer to finding the cause or the cure of FSGS. Scientists tell us that much more research needs to be done on the basic science behind the disease.

NephCure Foundation, the University of Michigan, and other important university research health centers have come together along with the NIH to support the establishment of the *Nephrotic Syndrome Rare Disease Clinical Research Network*. This network is a new collaboration between research institutions, the NephCure Foundation, and NIH supporting research on NS and FSGS. This initiative has tremendous potential to make significant advancements in NS and FSGS research by pooling efforts and resources, including populations for clinical trials. The addition of federal resources to this important initiative is crucial to ensuring the best possible outcomes for the *Nephrotic Syndrome Rare Disease Clinical Research Network* occur.

NCF is also grateful to the NIDDK for issuing of a program announcement (PA) that serves to initiate grant proposals on glomerular disease; the PA, issued in March of 2007, is glomerular-disease specific. The announcement will utilize the R01 mechanism to award researchers funding. In February of 2010 the PA was re-released for a further 3 years.

We ask the Subcommittee to encourage the ORDR to continue to support the *Nephrotic Syndrome Rare Disease Clinical Research Network* to expand FSGS research. We also ask the Subcommittee to encourage NIDDK to continue to issue glomerular disease program announcements.

Too Little Education About a Growing Problem

When glomerular disease strikes, the resulting NS causes a loss of protein in the urine and edema. The edema often manifests itself as puffy eyelids, a symptom that many parents and physicians mistake as allergies. With experts projecting a substantial increase in nephrotic syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

It would be of great benefit for CDC to begin raising public awareness of the glomerular diseases in an attempt to diagnose patients earlier.

We ask the Subcommittee to encourage CDC to establish a glomerular disease education and awareness program aimed at both the general public and health care providers.

Glomerular Disease Strikes Minority Populations

Nephrologists tell us that glomerular disease strikes African Americans nearly 5 times more frequently than white Americans. No one knows why this is, but some studies have suggested that the MYH9 gene, which is 5 times more prevalent in African Americans, may be linked to susceptibility to FSGS. NIDDK will be sponsoring a conference on this issue on April 19-20, 2010.

We ask that the NIH pay special attention to why this disease affects African-Americans to such a large degree and often in a more severe manner. The NephCure Foundation wishes to work with the NIDDK and the National Center for Minority Health and Health Disparities (NCMHD) to encourage the creation of programs to study the high incidence of glomerular disease within the African American population.

There is also evidence to suggest that the incidence of glomerular disease is higher among Hispanic Americans than in the general population. An article in the February 2006 edition of the NIDDK publication *Recent Advances and Emerging Opportunities*, discussed the case of Frankie Cervantes, a six year old boy of Mexican and Panamian descent. Frankie has FSGS received a transplanted kidney from his mother. We applaud the NIDDK for highlighting FSGS in their publication, and for translating the article about Frankie into both English and Spanish. Only through similar efforts at cross-cultural education can the African-American and Hispanic-American communities learn more about glomerular disease.

The *Nephrotic Syndrome Rare Disease Clinical Research Network* offers an excellent opportunity for NCMHD to collaborate with a wide variety of researchers and institutions to increase knowledge of NS/FSGS. The addition of NCMHD would add additional insight into the minority community, which is so disproportionately impacted by FSGS.

We ask the Subcommittee to encourage ORDR, NIDDK, and NCMHD to collaborate on research that studies the incidence and cause of this disease among minority populations. We also ask the Subcommittee to urge NIDDK and the NCMHD undertake culturally appropriate efforts aimed at educating minority populations about glomerular disease.

**Testimony Submitted to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education**

**Karen Peluso, Executive Director, Neurofibromatosis, Inc., Northeast
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April 16, 2010

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for Neurofibromatosis (NF), a terrible genetic disorder closely linked to cancer, learning disabilities, heart disease, memory loss, brain tumors, and other disorders affecting up to 175 million Americans in this generation alone. Thanks in large measure to this Subcommittee's strong and enduring support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

On behalf of Neurofibromatosis, Inc., Northeast, a participant in a national coalition of NF advocacy groups, I speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases linked to NF.

What is Neurofibromatosis (NF)?

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and/or death. NF can also cause other abnormalities such as unsightly benign tumors across the entire body and bone deformities. In addition, approximately one-half of children with NF suffer from learning disabilities. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

NF is not rare. It is three times more common than Muscular Dystrophy and Cystic Fibrosis combined, but is not widely known because it has been poorly diagnosed for many years. Approximately 100,000 Americans have NF, and it appears in approximately one in every 2,500 births. It strikes worldwide, without regard to gender, race or ethnicity. Approximately 50 percent of new NF cases result from a spontaneous mutation in an individual's genes, and 50 percent are inherited. There are two types of NF: NF1, which is more common, and NF2, which primarily involves tumors causing deafness and balance problems. In addition, advances in NF research stand to benefit over 175 million Americans in this generation alone because NF, the most common neurological disorder caused by a single gene, is directly linked to many of the most common diseases affecting the general population.

If a child was diagnosed with NF it would mean tumors could grow anytime, anywhere on his/her nervous system, from the day he/she was born until the day he/she died with no way to predict when or how severely the tumors would affect his/her body - and no viable way to treat the disease outside of surgery - which often results in more tumors that grow twice as fast. That same child would then have a 50% chance to pass the gene to his/her children. That's an overwhelming diagnosis and it bears repeating: NF is one of the most common genetic disorders

in our country and has no cure and no viable treatment. But that is changing. The immediate future holds real promise.

Link to Other Illnesses

Researchers have determined that NF is closely linked to cancer, heart disease, learning disabilities, memory loss, brain tumors, and other disorders including deafness, blindness and orthopedic disorders.

Cancer – NF is closely linked to many of the most common forms of human cancer, affecting approximately 65 million Americans, because of its tumor suppresser function. Research has demonstrated that NF’s tumor suppressor protein, neurofibromin, inhibits RAS, one of the major malignancy causing growth proteins involved in 30 percent of all cancer. Accordingly, advances in NF research may well lead to treatments and cures not only for NF patients but for all those who suffer from cancer and tumor-related disorders. Similar studies have also linked epidermal growth factor receptor (EGF-R) to malignant peripheral nerve sheath tumors (MPNSTs), a form of cancer which disproportionately strikes NF patients.

Heart disease – Researchers have demonstrated that mice completely lacking in NF1 have congenital heart disease that involves the endocardial cushions which form in the valves of the heart. This is because the same *ras* involved in cancer also causes heart valves to close. Neurofibromin, the protein produced by a normal NF1 gene, suppresses *ras*, thus opening up the heart valve. Promising new research has also connected NF1 to cells lining the blood vessels of the heart, with implications for other vascular disorders including hypertension, which affects approximately 50 million Americans. Researchers believe that further understanding of how an NF1 deficiency leads to heart disease may help to unravel molecular pathways affected in genetic and environmental causes of heart disease.

Learning disabilities – Learning disabilities are the most common neurological complication in children with NF1. Research aimed at rescuing learning deficits in children with NF could open the door to treatments affecting 35 million Americans and 5 percent of the world’s population who also suffer from learning disabilities. Leading researchers have already rescued learning deficits in both mice and fruit flies with NF1 with a number of drugs, and clinical trials have now been approved by the FDA. This NF research could potentially save federal, state, and local governments, as well as school districts billions of dollars annually in special education costs resulting from a treatment for learning disabilities. It also holds enormous implications for understanding and treating associated social and behavioral problems in children who suffer from learning disabilities.

Memory Loss – Researchers have also determined that NF is closely linked to memory loss and are now investigating conducting clinical trials with drugs that may not only cure NF’s cognitive disorders but also result in treating memory loss as well with enormous implications for patients who suffer from Alzheimer’s disease and other dementias.

Deafness – NF2 accounts for approximately 5 percent of genetic forms of deafness. It is also related to other types of tumors, including schwannomas and meningiomas, as well as being a major cause of balance problems.

Scientific Advances

Thanks in large measure to this Subcommittee's support; scientists have made enormous progress since the discovery of the NF1 gene in 1990. Major advances in just the past few years have ushered in an exciting era of clinical and translational research in NF with broad implications for the general population.

These recent advances have included:

- Phase II and Phase III clinical trials involving new drug therapies for both cancer and cognitive disorders;
- Creation of a National Clinical and Pre-Clinical Trials Infrastructure and NF Centers;
- Successfully eliminating tumors in NF1 and NF2 mice with the same drug;
- Developing advanced mouse models showing human symptoms;
- Rescuing learning deficits and eliminating tumors in mice with the same drug;
- Determining the biochemical, molecular function of the NF genes and gene products;
- Connecting NF to more and more diseases because of NF's impact on many body functions.

Future Directions

NF research has now advanced to the translational and clinical stages which hold incredible promise for NF patients, as well as for patients who suffer from many of the diseases linked to NF. This research is costly and will require an increased commitment on the federal level. Specifically, future investment in the following areas would continue to advance research on NF:

- Clinical trials;
- Funding of clinical trials network to connect patients with experimental therapies;
- DNA Analysis of NF tissues;
- Development of NF Centers, tissue banks, and patient registries;
- Development of new drug and genetic therapies;
- Further development of advanced animal models;
- Expansion of biochemical research on the functions of the NF gene and discovery of new targets for drug therapy; and
- Natural history studies and identification of modifier genes – studies are already underway to provide a baseline for testing potential therapies and differentiate among different phenotypes of NF.

Congressional support for NF research

The enormous promise of NF research – and its potential to benefit over 175 million Americans in this generation alone – has gained increased recognition from Congress and the NIH. This is evidenced by the fact that eleven institutes at NIH are currently supporting NF research (NCI, NHLBI, NINDS, NIDCD, NHGRI, NCRR, NIMH, NIGMS, NEI, NIA, and OD), and NIH's total research portfolio has increased from \$3 million in FY1990 to an estimated \$18 million in FY 2010. However, we are concerned that the NF research portfolio at NIH has remained flat in recent years, despite promising research and appropriations report language recommending a

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greater investment. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that NIH will substantially increase NF research funding.

We appreciate the Subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued.

Thank you again for the opportunity to tell you of the progress and potential of NF research.

**STATEMENT OF JOSEPH FAY
CHAIR, NORTH AMERICAN BRAIN TUMOR COALITION
Submitted to the Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations
United States House of Representatives**

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It is my pleasure as Chair of the North American Brain Tumor Coalition to submit this statement in favor of a strong federal investment in biomedical research, an investment that is critically important to improving the treatments for brain tumors. For individuals with brain tumors, the possibility of surviving their diagnosis with a good quality of life depends on research and development of new treatments. Our recommendations to the subcommittee are intended to advance that research.

The North American Brain Tumor Coalition and Its Members

The North American Brain Tumor Coalition is a network of nine brain tumor organizations. Our members are the Brain Tumor Awareness Organization, Brain Tumour Foundation of Canada, Children's Brain Tumor Foundation, Florida Brain Tumor Association, Michael Quinlan Brain Tumor Foundation, National Brain Tumor Society, Preuss Foundation, Southeastern Brain Tumor Foundation, and Voices Against Brain Cancer.

Many of the members of the Coalition raise private funds to support brain tumor research, while also undertaking patient and family support initiatives. Almost all of our members disseminate educational materials about brain tumors, and many also have forums for collaboration and cooperation among brain tumor researchers. The diversity of our organizations reflects the serious and far-reaching impact of brain tumors on patients and their families. We are pleased to have a Canadian organization in the Coalition, an important sign of international collaboration among brain tumor organizations. The fact that the Coalition includes organizations outside the United States is also a recognition of the fact that brain tumors respect no borders.

The North American Brain Tumor Coalition brings these diverse organizations together to focus on advocacy on behalf of those with brain tumors. We are dedicated to improving the prognosis and quality of life for brain tumor patients. In order to achieve these goals, there must be an increased investment in research to understand the causes of brain tumors, improve brain tumor treatments, and strengthen neuro-rehabilitation services for those treated for brain tumors.

Brain Tumors and Their Impact

Brain tumors are not a single disease; there are approximately 126 types of primary brain tumors. The diversity of brain tumors contributes to the complexity of research in this field. Many of the

126 tumors classified as “brain tumors” are not in the brain but instead arise from structures that are associated with the brain. These include tumors of the membranes covering the brain (referred to as meningiomas) or adjacent cranial and paraspinal nerves (schwannomas). Brain tumors may be benign (most meningiomas are benign) to highly aggressive (glioblastomas). Both children and adults are diagnosed with brain tumors.

It is estimated that there will be more than 62,000 cases of primary malignant and non-malignant brain and central nervous system tumors in the United States in 2010.¹ There will be approximately 10,000 primary brain tumors in Canada in 2010. In 2010, it is estimated that 4,030 new primary brain tumors (malignant and non-malignant) will be diagnosed in children in the United States in 2010. Of the 4,030 new cases, an estimated 2,880 will be in children under the age of 15.²

Approximately 612,000 Americans are living with a primary brain tumor.³

The American Cancer Society estimates that almost 12,920 deaths in 2009 will be attributed to primary malignant brain tumors.⁴ This total does not include those who will die from primary non-malignant brain tumors.

Many tens of thousands – 140,000 or more – are diagnosed with metastatic brain tumors each year. Many tumor types can spread to the brain, but the most common are lung cancer, breast cancer, melanoma, kidney cancer, bladder cancer, and testicular cancer. It is estimated that metastatic brain tumors occur in 10 to 30% of adult cancers, and in one fourth of all cancers that metastasize.⁵

These statistics about incidence, prevalence, and mortality are important, but they do not fully convey the burden of brain tumors. For many brain tumor patients, treatments are inadequate. Those who receive treatments that do extend their lives may nonetheless experience serious side-effects from their brain tumors and treatment, side-effects that require intervention. In addition, a diagnosis with a brain tumor does not only affect the patient; it also has a profound effect on the patient’s family and friends.

A study published in the *Annals of Internal Medicine* on April 6, 2010, describes the impact of a cancer diagnosis on children. The study notes that there have been significant improvements in treatments for some pediatric cancers. However, cancer treatments often cause serious health problems, including but not limited to second cancers and heart conditions. The researchers used computer models to estimate what happens to childhood cancer survivors and determined that survivors of brain cancer died about 18 years earlier than the general population. This study underscores the problems confronted by brain tumor patients who “survive” their diagnosis.

¹ Central Brain Tumor Registry, 2004-2006.

² Central Brain Tumor Registry, 2004-2006.

³ Porter KR, McCarthy BJ, Freels S, et al., Prevalence estimates for primary brain tumors in the US by age, gender, behavior, and histology. *Neuro-Oncology*, In press.

⁴ American Cancer Society, *Cancer Facts & Figures 2009*, Atlanta, 2009.

⁵ Medline Plus, National Library of Medicine, accessed on April 7, 2010.

The Challenges of Brain Tumor Treatment and Research

In a report dated 2000, the Brain Tumor Progress Review Group, convened by the National Cancer Institute (NCI) and National Institute of Neurological Disorders and Stroke (NINDS), stated that the difficulty in treating brain tumors relates to the unique biology of the brain, including the fact the brain is enclosed in a bony canal that allows little room for tumor growth, brain tumors invade normal tissue and make surgical removal impossible, brain tumors are protected by the blood-brain barrier, the brain is rich in expressed genes and therefore is a fertile field for growth of brain tumors, and brain tumors appear to be less susceptible to attack by the immune system than tumors in other organs.

The complexity and diversity of brain tumors make the work of brain tumor researchers very difficult. For this reason, an aggressive and balanced approach to brain tumor research is necessary. The research effort must be strongly supported by the National Institutes of Health (NIH), as described below.

NABTC Recommendations for National Institutes of Health Funding

The North American Brain Tumor Coalition supports the recommendations of many other biomedical research and patient advocacy organizations that NIH funding be increased to \$35 billion in fiscal year 2011. This amount is necessary to sustain the commitment of the American Recovery and Reinvestment Act and prevent disruptions in the work of outstanding scientists committed to a wide range of research topics. The Coalition understands that this is a very aggressive recommendation in the current economic and budget climate, but this ambitious level of funding is necessary if additional advances in basic and applied science are to be achieved.

A recent accomplishment in brain tumor research underscores the need for additional resources and a sustained federal commitment in order to realize improvements in the quality of treatments for many diseases and quality of life for those who are diagnosed with those diseases. The Cancer Genome Atlas (TCGA) at NCI announced in January 2010 that researchers in TCGA Research Network had determined that glioblastoma multiforme (GBM) is not a single disease but four distinct molecular subtypes. In announcing the research findings, TCGA said that the research might lead to a more personalized approach to GBM, one of the deadliest of all brain tumors.

The North American Brain Tumor Coalition applauds the important research finding of TCGA but also notes that the finding points to the need for additional research, including:

- Work to understand the molecular classification of other brain tumors, in addition to GBM;
- Research to translate basic research findings into treatment approaches;
- Identification of agents that might be evaluated in brain tumors, including those that are newly subject to a molecular classification scheme; and
- Clinical testing of possible new agents for brain tumor treatment.

In short, the findings of TCGA point the way to a new approach to brain tumor treatment, but we have only taken the first step in a long journey to effective, personalized brain tumor treatments.

This translates to the need for a balanced research program that includes the following elements:

- Support for investigator-initiated research so that new and promising ideas from the nation's leading brain tumor researchers can be tested;
- Funding for The Cancer Genome Atlas and other efforts that are advancing the molecular classification of disease;
- Resources for translational programs to translate basic findings into new treatments; for brain tumor research, this means the continuation of the Specialized Programs of Research Excellence (SPORes) and the adult and pediatric brain tumor consortia;
- Support for clinical trials through the brain tumor consortia, cooperative groups, and cancer centers; and
- Aggressive and creative support for research on the late and long-term effects of brain tumor treatment, including research on interventions for these side effects.

We recommend that medulloblastoma be added to the list of cancers identified for further study through The Cancer Genome Atlas. We also encourage innovative strategies for data sharing in the SPORes program, including across SPORes sites. Research foundations and patient advocacy organizations are pioneering creative means for sharing clinical and research data, and we encourage NCI to consider some of these models for their applicability to SPORes sites and other research settings.

NABTC Recommends Strategies for Encouraging Collaboration

Brain tumor treatment is complex and multi-disciplinary, and research on these tumors must also have these characteristics. NCI and NINDS have established and supported a collaborative venture, the Neuro-Oncology Program, which takes a collaborative and cooperative approach to brain tumor research.

This cooperative research approach is absolutely critical for brain tumors, but it will yield benefits for many other diseases as well. The Coalition applauds the leadership of the NIH Director in encouraging collaborative ventures that yield communication and collaboration among institutes. We also recommend that more funding mechanisms be created to facilitate this sort of cooperation among academic research institutions seeking NIH funding.

Urgency in the Brain Tumor Research Program

It is necessary to keep a long view in biomedical research, sustaining funding levels and preventing disruptions in research. However, it is also important to have a sense of urgency about the pace of research. The five-year relative survival rate for primary malignant brain tumors is 33.6% for males and 37% for females. For these individuals, time is precious and the research effort – literally their lifeline – must be accelerated as much as possible.



Submitted by: Suzanne Begeny, PhD, RN
 Nursing Community
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**Testimony of the Nursing Community Regarding
 Fiscal Year 2011 Appropriations for the Title VIII Nursing Workforce Development
 Programs
 U.S. House Appropriations Subcommittee on Labor, Health and Human Services, and
 Education**

April 15, 2010

The Nursing Community is a forum for professional nursing and related organizations to collaborate on a wide spectrum of healthcare and nursing issues including practice, education, and research. These 53 organizations are committed to promoting America's health through nursing care. Collectively, the Nursing Community represents over 850,000 Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs), nurse executives, nursing students, nursing faculty, and nurse researchers. Together, our organizations work collaboratively to increase funding for the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) so that American nurses have the support needed to provide high quality care to their patients.

The National Nursing Shortage Continues to Impact Quality Care

Since 1998, the United States has experienced a significant shortage of RNs, which has dramatically impacted the quality of care provided by our nation's healthcare delivery system. In March 2007, a comprehensive report initiated by the federal Agency for Healthcare Research and Quality was released on *Nursing Staffing and Quality of Patient Care*. The authors found that the shortage of RNs, in combination with an increased workload, poses a potential threat to the quality of nursing care. In settings with inadequate nurse staffing, patient safety was compromised. However, increases in RN staffing were associated with reductions in hospital-related mortality and failure to rescue, as well as reduced lengths of stay. A robust supply of well-educated nurses is essential to ensure that all Americans receive quality health care and that our nation has the nurses necessary to meet the current and future demands.

The demand for nurses will continue to grow as the baby-boomer population ages, nurses retire, and the need for healthcare intensifies. According to the U.S. Bureau of Labor Statistics (BLS), nursing is the nation's top profession in terms of projected job growth with more than 581,000 new nursing positions being created through 2018 (a 22% increase in the workforce). Further, BLS analysts project that more than one million new and replacement nurses will be needed by 2016.

Currently, RNs comprise the largest group of health professionals with approximately 3.1 million providers offering essential care to patients in a variety of settings, including hospitals, long-term care facilities, community or public health areas, schools, workplaces, and home care. In addition, many nurses receive graduate degrees that allow them to practice autonomously as APRNs; become nurse faculty, nurse researchers, nurse administrators, and public health nurses; and work in the policy area to help shape healthcare delivery. With the new health reform law focused on creating a system that will increase access to quality care, emphasize prevention, and decrease cost, it is critical that a substantial investment be made in our healthcare workforce, particularly an investment in nurses. RNs and APRNs are vital to ensuring direct availability to high quality, cost-effective health care in a reformed system. Nurses are involved in every aspect of health care, and if the nursing workforce is not strengthened, the healthcare system will continue to suffer.

Reversing the Nursing Shortage: A Federal Solution

Throughout previous nursing shortages, particularly in the 1960s and 1970s, the federal government has offered relief to nursing schools and students to reverse the negative trend. In particular, the Nursing Workforce Development programs offered viable solutions to nursing shortages, expanded nursing school programs, increased the number of nurse faculty, and helped ensure nurses were practicing in areas with a critical shortage. As Congress searches for programs to address the nursing shortage now and in the future, the Title VIII programs have been and continue to be a proven solution.

Nursing Workforce Development Programs

The Nursing Workforce Development programs have supported the supply and distribution of qualified nurses to meet our nation's healthcare needs since 1964. Over the last 46 years, these programs have addressed all aspects of nursing shortages – education, practice, retention, and recruitment. The Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. Between FY 2006 and 2008, the Title VIII programs supported 214,575 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities. Today, the Title VIII programs are essential to solving the current national nursing shortage.

Title VIII Effectiveness

Results from the American Association of Colleges of Nursing's (AACN) *2009-2010 Title VIII Student Recipient Survey* included responses from 1,420 students who noted that these programs played a critical role in funding their nursing education. The survey showed that three-quarters of the students receiving Title VIII funding are attending school full-time. By supporting full-time students, the Title VIII programs are helping to ensure that students enter the workforce without delay. The programs also address the current demand for primary care providers. A high percentage of the students surveyed (49.1%) reported that their career goal is to become a nurse practitioner. Approximately 80% of nurse practitioners provide primary care services throughout the United States. Additionally, the nurse faculty shortage continues to inhibit the ability of nursing schools to increase student capacity and address the shortage. Of the students who responded to the survey, 40.5% stated their ultimate career goal was to become nurse faculty.

Nursing Students Supported by Title VIII Funding

Of the Title VIII student recipients surveyed, 39% reported that they received between \$1,001-\$3,000 in funding over one year. Sixty-seven percent reported that this funding supported a portion of their tuition, and 35.8% reported that the funding was dedicated to books and educational materials. Fifty-two percent of the students responded that the Title VIII funding paid for 25% or less of their total student loans. Of those students, 26% stated that the funding paid for less than 5% of their total nursing student loans. When asked how the Title VIII programs could be improved, the overwhelming response from students was to increase the funding in order to provide higher levels of support for their education.

Nursing students rely upon support through Title VIII to complete their degree and offset their considerable educational expenses. Continued and increased support for the Title VIII programs can help address the demand for nursing services.

The Nursing Community respectfully request \$267.3 million (a 10% increase) for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in FY 2011. Last year, your Subcommittee provided a significant funding boost for Title VIII that helped support the Loan Repayment program and Scholarship and Nurse Faculty Loan program. These increases will bolster the pipeline of nurses and nurse faculty, which is so critical to reversing the nursing shortage. We feel it is extremely important to maintain last year's funding level for these critical programs in FY 2011 and direct the 10% requested increase for the four Title VIII program that have not kept pace with inflation since FY 2005. The Advanced Education Nursing, Nursing Workforce Diversity, Nurse Education, Practice, and Retention, and Comprehensive Geriatric Education programs expand nursing school capacity and increase patient access to care. These programs would greatly benefit from the 10% increase awarded in proportion to their FY 2010 funding level. Below is a description of these four critical programs.

Advanced Education Nursing (AEN) Grants (Sec. 811) support the preparation of RNs in master's and doctoral nursing programs. The AEN grants help to prepare our nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and other nurse specialists requiring advanced education. In FY 2008 (most current data available), these grants supported the education of 5,649 students.

- **AEN Traineeships** assist graduate nursing students by providing full or partial reimbursement for the costs of tuition, books, program fees and reasonable living expenses. In FY 2008, this funding helped support 6,675 graduate nurses and APRNs.
- **Nurse Anesthetist Traineeships (NAT)** support the education of students in nurse anesthetist programs. In some states, Certified Registered Nurse Anesthetists (CRNAs) are the sole anesthesia providers in almost 100% of rural hospitals. Much like the AEN Traineeships, the NAT provides full or partial support for the costs of tuition, books, program fees, and reasonable living expenses. In FY 2008, the program supported 2,145 future CRNAs.

Workforce Diversity Grants (Sec. 821) prepare disadvantaged students to become nurses. This program awards grants and contract opportunities to schools of nursing, nurse managed health centers, academic health centers, state or local governments, and nonprofit

entities looking to increase access to nursing education for disadvantaged students, including racial and ethnic minorities under-represented among RNs. In FY 2008, the program supported 11,638 students.

Nurse Education, Practice, and Retention Grants (Sec. 831) help schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and healthcare facilities strengthen programs that provide nursing education. In FY 2008, the priority areas under this program supported 42,761 with an additional 455 students supported by the Integrated Nurse Education Technology program.

Comprehensive Geriatric Education Grants (Sec. 855) are awarded to schools of nursing or healthcare facilities to better provide nursing services for the elderly. These grants are used to educate RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, prepare faculty members, and provide continuing education. In FY 2008, this program supported 6,514 nurses and nursing students.

Without an adequate supply of nurses to care for our nation, including our growing aging population, the healthcare system is not sustainable. The Nursing Community's request of \$267.3 million in FY 2011 for the HRSA Nursing Workforce Development programs will help ensure access to quality care provided by America's nursing workforce.

Members of the Nursing Community Submitting this Testimony

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| Academy of Medical-Surgical Nurses | Gerontological Advanced Practice Nurses Association |
| American Academy of Ambulatory Care Nursing | Hospice and Palliative Nurses Association |
| American Academy of Nurse Practitioners | Infusion Nurses Society |
| American Academy of Nursing | National Association of Clinical Nurse Specialists |
| American Association of Colleges of Nursing | National Association of Hispanic Nurses |
| American Association of Nurse Anesthetists | National Association of Nurse Practitioners in Women's Health |
| American College of Nurse Practitioners | National Association of Pediatric Nurse Practitioners |
| American College of Nurse-Midwives | National Black Nurses Association |
| American Nurses Association | National Nursing Centers Consortium |
| American Organization of Nurse Executives | National Organization of Nurse Practitioner Faculties |
| American Psychiatric Nurses Association | National Student Nurses' Association, Inc |
| American Society for Pain Management Nursing | Nurses Organization of Veterans Affairs |
| Association of Community Health Nursing Educators | Oncology Nursing Society |
| Association of Nurses in AIDS Care | Preventive Cardiovascular Nurses Association |
| Association of periOperative Registered Nurses | Public Health Nursing Section, American Public Health Association |
| Association of Rehabilitation Nurses | Society of Urologic Nurses and Associates |
| Association of Women's Health, Obstetric and Neonatal Nurses | Wound, Ostomy and Continence Nurses Society |
| Commissioned Officers Association of the U.S. Public Health Service | |
| Dermatology Nurses' Association | |



**Testimony of
David Mandel
Chief Executive Officer
Ohel Children's Home and Family Services
Phone: (718) 851-6555 / Email: DM@ohelfamily.org
Submitted to the Labor/HHS/Education Subcommittee
of the House Appropriations Committee
on Friday April 16, 2010**

Chairman Obey and members of the Subcommittee:

Thank you for this opportunity today to discuss two important programs coordinated by Ohel Children's Home and Family Services for individuals in New York: (1) the **Ohel Foster Care Program**, for which \$585,000 in Fiscal Year 2011 funding is being requested through the U.S. Department of Health and Human Services through the Administration for Children and Families; and (2) the **Ohel Family Case Management Program**, for which \$613,000 is being requested through the U.S. Department of Health and Human Services, Office of the Secretary.

Background on Ohel Children's Home and Family Services

Ohel Children's Home and Family Services is a pioneering, not-for-profit social services organization committed to elevating lives of individuals with mental illness, developmental disabilities and families in crisis throughout the New York Metropolitan area. Services are also provided in New Jersey and South Florida. Since 1969, Ohel has served abandoned, abused, and neglected children, as well as families in crisis. Ohel strives to deliver services of excellence in a culturally sensitive manner through all phases of life. As an awareness driver, educator, and service provider, Ohel is proactive

in confronting community ailments and empowering professionals and others with the tools of prevention and support. Ohel positively impacts the way social issues are addressed in the community and consistently receives "Excellent" ratings in all of its programs from various licensing agencies.

The Need for Foster Care Assistance

Youth in foster care are among our nation's most vulnerable, typically entering foster care as a result of extreme physical abuse and neglect coupled with the trauma caused by the disruption to their family and home environment. These children face a wide range of social and psychological problems that can make it difficult for them to develop into viable, productive young adults. We are proud to share the fact that Ohel has been a top-ranked provider in the New York City foster care system for four consecutive years.

Under the auspices of New York City's Administration for Children's Services, Ohel's Foster Care program is designed to work towards the reunification of children with their biological families. The program provides the stability of a caring family for children who are unable to care for them due to illness or disability, or children who are removed from their parents' home due to conditions of abuse or neglect. Many of these children have serious emotional, psychological, and developmental problems that can lead to conflict with their families. Children who cannot be successfully placed in regular foster homes are placed in one of Ohel's congregate care residences.

Our residential program for Foster Care children is reserved for adolescents experiencing severe difficulties. We provide housing and personal needs, medical and psychological care, schooling, vocational training, as well as other services necessary to prepare these young men and women for adulthood and independent living.

Ohel professionals ensure that each child's unique emotional and educational needs are met. Our Foster Care Program also provides training and counseling to birth parents and to foster parents and their children, ensuring the transition is as smooth as possible for all. As part of this initiative, Ohel is committed to providing specialized services, above and beyond what may be required. These include:

- Intensive crisis intervention;
- Integrative treatment approach;
- Community education focused on prevention;
- Training of professionals and paraprofessionals;
- Recreation and camp opportunities;
- Transportation services to facilitate birth parents and child visits in order to expedite permanency for children;
- Psychiatric and psychological treatment;
- Prevention services; and
- Reduced child / case manager ratio.

Crisis intervention services and psychiatric and psychological treatment for foster children, coupled with preventive activities, results in an increased level of permanency for foster children and a decrease in child abuse or neglect. This corrective experience ensures that children remain in long-term relationships with their parents and siblings, as well as enhances the chance of children either being reunited with their birth families or adopted, thereby complying with the federal standards of the Adoption and Safe Families Acts (ASFA) of 1997. Ohel also works with the families in an attempt to rehabilitate them, thus preventing further child abuse of all kinds.

Providing Case-Management Assistance for Families in Need

Families serve the most critical role in the healthy development of a child. When parents are not able to adequately provide for a child's physical or emotional needs, society pays a high price in terms of increased incidence of physical and mental illness, poor academic performance, and juvenile delinquency. When parents are stressed by multiple factors such as financial difficulties, unemployment, poor parenting role models, substance abuse and mental illness, their children are at great risk.

By providing various social services for children and families over the last 40 years, Ohel has come to recognize stressors that oftentimes put a family at risk for falling into a crisis. In order to prevent a negative situation, Ohel has developed a program that targets families at risk to assist them in managing various aspects of their lives so as to prevent a crisis from taking its toll on the health, stability and well being of all individuals in the family. Ohel's family support program provides intensive case management to families in need of support, through the following services:

- Parenting skills training;
- Budgeting and money management skills development;
- Stress reduction, self care and health maintenance counseling;
- Emergency cash assistance;
- Coaching regarding effective communication skills between parent and child, spouse/partner, and conflict resolution; and
- Screening, assessment and treatment for mental illness or substance abuse.

Ohel's Family Case Management Program targets individuals and families that are at-risk and have one or more of the following psycho-social stressors:

1. A family member who suffers from unemployment or underemployment;
2. A family member who does not have a high school diploma;
3. A family member who became a parent as a teen;
4. A family member who has been the victim of abuse as a child;
5. Single parent households;
6. A family member suffering from a significant mental illness, e.g. Depression, Schizophrenia, Bi-Polar or Obsessive Compulsive Disorder; and/or

7. A child who has a developmental disability, performing below grade level, or is suffering from severe emotional disturbance.

With proactive intervention and prevention, we believe that many families can better manage their challenging situations and continue to operate as a family unit despite their difficulties. The Ohel Family Case Management Program seeks to help those families at risk to prevent a crisis and thus preserve the family unit, while saving the individual family members from trauma, and helping to save taxpayer money on the costs of providing additional intervention and social services.

Mr. Chairman, with Federal support, Ohel seeks to provide assistance to vulnerable families through both our Foster Care Program and our Case Management Program. The goal of both programs – as well as the mission of our organization – is to help children and families in crisis so that all individuals may live healthy and productive lives. I thank you again for your time and attention to these important programs.

Oncology Nursing Society
Written Testimony to the House Labor-Health and Human Services
Appropriations Subcommittee
Regarding Fiscal Year 2011 Nursing and Cancer Related Funding
Submitted by: Paula Rieger, CEO Oncology Nursing Society
(412) 859-6314 and prieger@ons.org
April 16, 2010

Overview

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding fiscal year (FY) 2011 funding for cancer and nursing related programs. ONS, the largest professional oncology group in the United States, composed of more than 37,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good.

In 2009, an estimated 1.48 million Americans will be diagnosed with cancer, and more than 562,340 will lose their battle with this terrible disease; at the same time the national nursing shortage is expected to worsen. Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older.¹ Despite these grim statistics, significant gains in the war against cancer have been made through our nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless, unless we can deliver them to all Americans in need. Moreover, a recent survey of ONS members found that the nursing shortage is having an impact in oncology physician offices and hospital outpatient departments. Some respondents indicated that when a nurse leaves their practice, they are unable to hire a replacement due to the shortage – leaving them short-staffed and posing scheduling challenges for the practice and the patients. These vacancies in all care settings create significant barriers to ensuring access to quality care.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates ongoing and significant federal funding for cancer research and application, as well as funding for programs that help ensure an adequate oncology nursing workforce to care for people with cancer. ONS stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the nation's nursing workforce. We thank the Subcommittee for its consideration of our FY 2011 funding request detailed below.

Securing and Maintaining an Adequate Oncology Nursing Workforce

Oncology nurses are on the front lines in the provision of quality cancer care for individuals with cancer – administering chemotherapy, managing patient therapies and side-effects, working with insurance companies to ensure that patients receive the appropriate treatment, providing treatment education and counseling to patients and family members, and engaging in myriad

¹ American Cancer Society. *Cancer Facts and Figures 2009*.
<http://www.cancer.org/downloads/STT/500809web.pdf>

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other activities on behalf of people with cancer and their families. Cancer is a complex, multifaceted chronic disease, and people with cancer require specialty-nursing interventions at every step of the cancer experience. People with cancer are best served by nurses specialized in oncology care, who are certified in that specialty.

As the overall number of nurses is expected to decline in the coming years, we likely will experience a commensurate decrease in the number of nurses trained in the specialty of oncology. With an increasing number of people with cancer needing high-quality health care, coupled with an inadequate nursing workforce, our nation could quickly face a cancer care crisis of serious proportion, with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the *New England Journal of Medicine* found that nursing shortages in hospitals are associated with a higher risk of complications – such as urinary tract infections and pneumonia, longer hospital stays, and even patient death.² Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need, and patient health and well-being could suffer.

Of additional concern is that our nation also will face a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of cancer research nurses, progress against cancer will take longer because of scarce human resources coupled with the reality that some practices and cancer centers' resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, we are concerned that our nation may falter in its delivery and application of the benefits from our federal investment in research.

ONS greatly appreciates the increase in funding in FY 2010. This represents an investment in patient care. ONS joins our colleagues from all nursing sectors and specialties to request \$267.3 million, a 10% increase over last year's level, for the Health Resources and Services Administrations (HRSA) Title VIII programs in FY 2011. The Title VIII programs received a substantial increase in FY 2010. Funding for these programs increased from \$171.03 million to \$243.872 million, a 42.6% increase. In particular the Nursing Faculty Loan Program received a 117% increase and the Loan Repayment and Scholarship program received a 152% increase. However, the Advanced Education Nursing, Nursing Workforce Diversity, Comprehensive Geriatric Education, and Nurse Education, Practice, and Retention programs, which help complement the Loan Repayment and Scholarship programs, have not kept pace with inflation since FY 2005 and did not receive any increases last year. Therefore, ONS along with the

² Needleman J., Buerhaus P., Matke S., Stewart M., Zelevinsky K. "Nurse-Staffing Levels and the Quality of Care in Hospitals." *New England Journal of Medicine* 346:, (May 30, 2002): 1715-1722.

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Nursing Community is requesting that the 10% increase in funding be awarded to these four programs.

With additional funding in FY 2011, the HRSA Workforce Development Programs will have much-needed resources to address the multiple factors contributing to the nationwide nursing shortage. Advanced nursing education programs play an integral role in supporting registered nurses interested in advancing in their practice and becoming faculty. As such, these programs must be adequately funded in the coming year.

ONS strongly urges Congress to provide HRSA with a minimum of \$267.3 million in FY 2011 to ensure that the agency has the resources necessary to fund a higher rate of nursing scholarships and loan repayment applications and support other essential endeavors to sustain and boost our nation's nursing workforce. Nurses – along with patients, family members, hospitals, and others – have joined together in calling upon Congress to provide this essential level of funding. The National Coalition for Cancer Research (NCCR), a non-profit organization comprised of 23 national cancer organizations, and One Voice Against Cancer (OVAC), a collaboration of 39 national non-profit organizations, are also advocating \$267.3 million in FY 2011 for the Nurse Reinvestment Act. ONS and its allies have serious concerns that without full funding, the Nurse Reinvestment Act will prove an empty promise, and the current and expected nursing shortage will worsen, and people will not have access to the quality care they need and deserve.

Sustain and Seize Cancer Research Opportunities

Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joined with the broader health community in advocating a 13.5% increase (\$35.210 billion) for NIH in FY 2011. This level of investment will allow NIH to sustain and build on its research progress, while avoiding the severe disruption to advancement that could result from a minimal increase. Cancer research is producing amazing breakthroughs – leading to new therapies that translate into longer survival and improved quality of life for cancer patients. In recent years, we have seen extraordinary advances in cancer research, resulting from our national investment, which have produced effective prevention, early detection, and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate \$5.795 billion to the National Cancer Institute (NCI), as well as \$240 million to the National Center for Minority Health and Health Disparities in FY 2011 to support the battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span – from management of patients during illness and recovery, to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into

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cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest, such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses, such as cancer. ONS joins with others in the nursing community and NCCR in advocating a FY 2011 allocation of \$160 million for NINR.

Boost Our Nation's Investment in Cancer Prevention, Early Detection, and Awareness

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening. Although the potential for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our nation does not invest sufficiently in these strategies. The nation must make significant and unprecedented federal investments today to address the burden of cancer and other chronic diseases, and to reduce the demand on the healthcare system and diminish suffering in our nation, both for today and tomorrow.

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering, at the community level, what is learned from research. Therefore, ONS joins with our partners in the cancer community in calling on Congress to provide additional resources for the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates the following FY 2011 funding levels for the following CDC programs:

- \$255 million for the National Breast and Cervical Cancer Early Detection Program;
- \$65 million for the National Cancer Registries Program;
- \$50 million for the Colorectal Cancer Prevention and Control Initiative;
- \$50 million for the Comprehensive Cancer Control Initiative;
- \$25 million for the Prostate Cancer Control Initiative;
- \$5 million for the National Skin Cancer Prevention Education Program;
- \$10 million for the Gynecologic Cancer and Education and Awareness (Johanna's Law);
- \$10 million for the Ovarian Cancer Control Initiative; and
- \$6 million for the Geraldine Ferraro Blood Cancer Program.

Conclusion

ONS maintains a strong commitment to working with Members of Congress, other nursing and oncology groups, patient organizations, and other stakeholders to ensure that the oncology nurses of today continue to practice tomorrow, and that we recruit and retain new oncology nurses to meet the unfortunate growing demand that we will face in the coming years. By providing the

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FY 2011 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our nation continues to make gains in our fight against cancer.

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**The Ovarian Cancer National Alliance
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related
Agencies
Department of Health and Human Services**

The Ovarian Cancer National Alliance (the Alliance) appreciates the opportunity to submit comments for the record regarding the Alliance's fiscal year (FY) 2011 funding recommendations. We believe these recommendations are critical to ensure advances to help reduce and prevent suffering from ovarian cancer. For 13 years, the Alliance has worked to increase awareness of ovarian cancer and advocated for additional federal resources to support research that would lead to more effective diagnostics and treatments.

As an umbrella organization with 49 state and local organizations, the Alliance unites the efforts of survivors, grassroots activists, women's health advocates and health care professionals to bring national attention to ovarian cancer. Our sole mission is to conquer ovarian cancer.

According to the American Cancer Society, in 2009, more than 22,000 American women were diagnosed with ovarian cancer and approximately 15,000 lost their lives to this terrible disease. Ovarian cancer is the fifth leading cause of cancer death in women. Currently, more than half of the women diagnosed with ovarian cancer will die within five years. While ovarian cancer has early symptoms, there is no early detection test. Most women are diagnosed in Stage III or Stage IV, when survival rates are low. If diagnosed early, more than 90 percent of women will survive for five years, but when diagnosed later, less than 30 percent will.

In addition, only a few treatments have been approved by the Food and Drug Administration (FDA) for ovarian cancer treatment. These are platinum-based therapies and women needing further rounds of treatment are frequently resistant to them. More than 70 percent of ovarian cancer patients will have a recurrence at some point, underlying the need for treatments to which patients do not grow resistant.

For all of these reasons, we urgently call on Congress to appropriate funds to find solutions.

As part of this effort, the Alliance advocates for continued federal investment in the Centers for Disease Control and Prevention's (CDC) Ovarian Cancer Control Initiative. The Alliance respectfully requests that Congress provide \$10 million for the program in FY 2011.

The Alliance also fully supports Congress in taking action on educating Americans about ovarian cancer through providing funding for Johanna's Law: The Gynecologic Cancer Education and Awareness Act [P.L. 109-475]. The Alliance respectfully requests that Congress provide \$10 million to implement Johanna's Law in FY 2011.

Further, the Alliance urges Congress to continue funding the Specialized Programs of Research Excellence (SPORes), including the five ovarian cancer sites. These programs are administered through the National Cancer Institute (NCI) of the National Institutes of Health (NIH). The Alliance respectfully requests that Congress provide \$5.795 to the National Cancer Institute for FY 2011.

Centers for Disease Control and Prevention

The Ovarian Cancer Control Initiative

As the statistics indicate, late detection and, therefore, poor survival are among the most urgent challenges we face in the ovarian cancer field. The CDC's cancer program, with its strong capacity in epidemiology and excellent track record in public and professional education, is well positioned to address these problems. As the nation's leading prevention agency, the CDC plays an important role in translating and delivering at the community level what is learned from research, especially ensuring that those populations disproportionately affected by cancer receive the benefits of our nation's investment in medical research.

Prompted by efforts from leaders of the Alliance and championed by Representative Rosa DeLauro – with bipartisan, bicameral support – Congress established the Ovarian Cancer Control Initiative at the CDC in November 1999. Congress' directive to the agency was to develop an appropriate public health response to ovarian cancer and conduct several public health activities targeted toward reducing ovarian cancer morbidity and mortality.

The CDC's Ovarian Cancer Control conducts research about early detection, treatment and survivorship nationwide to increase understanding of ovarian cancer. Some ongoing research includes studying: the relationship between recorded symptoms, time to diagnosis, and ovarian cancer histology, the availability of gynecologic oncologists for ovarian cancer care, and frequency of symptoms in women aged 65 years and older with ovarian cancer as compared to a matched cohort of cancer-free women, among many other research projects.

Johanna's Law: The Gynecologic Cancer Education and Awareness Act

It is critical for women and their health care providers to be aware of the signs, symptoms and risk factors of ovarian and other gynecologic cancers. Often, women and providers

mistakenly confuse ovarian cancer signs and symptoms with those of gastrointestinal disorders or early menopause. While symptoms may seem vague – bloating, pelvic or abdominal pain, increased abdominal size and bloating and difficulty, eating or feeling full quickly, or urinary symptoms (urgency or frequency) – they can be deadly without proper medical intervention.

In recognition of the need for awareness and education, Congress unanimously passed Johanna's Law in 2006, enacted in early 2007. This law provides for an education and awareness campaign that will increase providers' and women's awareness of all gynecologic cancers including ovarian.

Thanks to funding under Johanna's Law, more women are learning how to identify the signs and symptoms of gynecologic. The Centers for Disease Control and Prevention have developed and disseminated over 275,000 fact sheets on gynecologic cancers in English and Spanish, created a web page dedicated to information about these diseases that receive over 1,500 hits a day, and are producing public service announcements for television scheduled to air beginning in September 2010. We must ensure that lifesaving information about gynecologic cancers continues to reach women.

With continued funding, the CDC will be able to continue to print and distribute brochures, maintain and update the web resources, develop additional educational materials such as posters for physician offices, complete continuing education materials for health care providers, and reach out to women beyond the original 40-60 year-old initial target group.

Support for Johanna's Law in the House of Representatives

A letter in support of the \$10 million funding request in FY 2011, signed by 46 Members of the House, was submitted to Chairman Obey and Ranking Member Tiahrt. The signers of the letter are Berkley, Berman, Burton, Capuano, Carnahan, Carson, Castor, Clarke, Connolly, Conyers, DeGette, Delahunt, DeLauro, Ellison, Frank, Grijalva, John Hall, Halvorson, Hinchey, Holt, Kildee, Kilroy, Peter King, Levin, LoBiondo, Lynch, Maloney, McGovern, Michaud, Christopher Murphy, Nadler, Napolitano, Norton, Oberstar, Peters, Pingree, Rush, Schakowsky, Scott, Titus, Van Hollen, Velazquez, Wasserman Schultz, Wu, and Yarmuth.

National Cancer Institute

Specialized Programs of Research Excellence in the National Institutes of Health

The Specialized Programs of Research Excellence were created by the NCI in 1992 to support translational, organ site-focused cancer research. The ovarian cancer SPORes began in 1999. There are five currently funded Ovarian Cancer SPORes located at the MD Anderson Cancer Center, the Fred Hutchinson Cancer Research Center, the Fox Chase Cancer Center, the Dana Farber/Harvard Cancer Center and the Mayo Clinic Cancer Center.

These SPORC programs have made outstanding strides in understanding ovarian cancer, as illustrated by their more than 300 publications as well as other notable achievements, including the development of an infrastructure between Ovarian SPORC institutions to facilitate collaborative studies on understanding, early detection and treatment of ovarian cancer.

Clinical Trials

The National Cancer Institute supports clinical research – the only way to test the safety and efficacy of potential new treatments for ovarian cancer. Two recent studies from NCI clinical trials show the impact of intraperitoneal chemotherapy in treating ovarian cancer (when chemotherapy is introduced directly into the woman’s abdominal cavity, rather than her bloodstream) and the importance of ultrasound expertise in properly diagnosing the disease.

NCI supports the Gynecology Oncology Group, a more than 50-member collaborative focusing on cancers of the female reproductive system. In 2007 alone, GOG published 23 articles about ovarian cancer.

Summary

The Alliance maintains a long-standing commitment to work with Congress, the Administration, and other policy makers and stakeholders to improve the survival rate for women with ovarian cancer through education, public policy, research and communication. Please know we appreciate and understand that our nation faces many challenges and Congress has limited resources to allocate; however, we are concerned that without increased funding to bolster and expand ovarian cancer education, awareness and research efforts, the nation will continue to see growing numbers of women losing their battle with this terrible disease.

On behalf of the entire ovarian cancer community – patients, family members, clinicians and researchers – we thank you for your leadership and support of federal programs that seek to reduce and prevent suffering from ovarian cancer. Thank you in advance for your support of \$10 million in FY 2011 funding for the CDC’s Ovarian Cancer Control Initiative and \$10 million in FY 2011 funding for Johanna’s Law as well as your continued support of the SPORC program, an appropriation of \$5.795 billion to NCI.

**Testimony of Julie Fleshman, JD, MBA
President & CEO**

Pancreatic Cancer Action Network

**Contact: Megan Gordon Don – Director of Government Affairs
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**To the House Appropriations Subcommittee on Labor, Health and Human Services,
Education & Related Agencies**

**On Pancreatic Cancer Research Funding at the National Cancer Institute for
Fiscal Year 2011**

Mr. Chairman and members of the Subcommittee-

First and foremost, I want to thank you for your leadership and support for medical research carried out under the auspices of the National Institutes of Health (NIH). Your continuing support recognizes that the basic resource of this country is its people, and the nation's strength can be no greater than the health of its citizenry.

On behalf of the patients, families and scientists who make up the Pancreatic Cancer Action Network, I especially thank you for helping to shine a spotlight on the fourth leading cause of cancer death in the United States and one of the most lethal forms of cancer: pancreatic cancer. Your vigilance and encouragement is helping to correct that situation. Unfortunately, of the over 42,000 diagnosed with pancreatic cancer last year, statistically, 76 percent died within 12 months of their diagnosis and 95 percent will die within 5 years. We therefore still have a long way to go before the diagnosis does not nearly guarantee a death sentence. And we have a long way to go before the only major cancer with a five-year survival rate *still* in the single digits enjoys the progress made against so many other forms of cancer.

Two years ago, this Subcommittee heard impassioned testimony from Dr. Randy Pausch, whose book, *The Last Lecture*, inspired millions of us to live our dreams, no matter what the challenges. He inspired us even though he was facing his toughest life challenge; he was battling pancreatic cancer.

Dr. Pausch's last appearance on Capitol Hill was in March 2008. He died four months later. His message was that we must change the research paradigm at NIH by providing more funding for the hardest research problems like pancreatic cancer because if we tackle the hardest problems, it will help us solve the easier problems.

Since Dr. Pausch's death there has been increased publicity of this deadly disease with the subsequent diagnosis and death of actor Patrick Swayze, and the diagnosis of U.S.

Supreme Court Justice Ruth Bader Ginsberg. Despite this publicity, the cold, hard fact remains that the number of new cases diagnosed and the number of deaths caused by pancreatic cancer are increasing. In fact, according to some experts, the number of new pancreatic cancer cases was projected to rise by 12 percent in 2009, and to *grow by 55 percent* by the year 2030. These are startling numbers. We must take action now to not only change the current statistics, but to ensure that we have the tools for the future.

But what patients, families, and advocates find most troubling is that while remarkable progress has been made against so many other forms of cancer, the progress we have made to detect or treat pancreatic cancer has changed little over the past 40 years:

- There is no early detection for pancreatic cancer and many of the risk factors are benign. As a result, the disease is usually diagnosed in its late stages, often after it has metastasized to other organs.
- There are no effective treatment options, except for a surgical procedure called the Whipple that only approximately 15 percent of all pancreatic cancer patients are eligible for and 80 percent of patients who have the surgery have a recurrence and die within five years.

So, why has progress in pancreatic cancer been so slow in coming? The answer is two-fold. The pancreas is complex and, because of its location, a difficult organ to study. But frankly, the real obstacle is the failure to make this a priority. Despite the fact that pancreatic cancer is the fourth-leading cause of cancer death in the U.S., historically less than two percent of the National Cancer Institute's (NCI's) budget is devoted to research in this field. I have included for the record a chart of NCI funding for the top five cancer killers – which includes pancreatic cancer – and their respective survival rates. This chart demonstrates in very dramatic fashion that there is a clear correlation between low investment in research and poor survival rates. When an investment has been made, the five year survival rates reflect those efforts.

In the absence of a concerted, well-focused scientific agenda, promising research applications go unfunded; opportunities to explore early screening techniques and more effective therapeutic agents are forgone; and investigators become discouraged and move to other fields of study.

Recommendations

How can the problem be corrected? Yes, funding for the NCI must be increased. In that regard, we join with our partners in the One Voice Against Cancer coalition to ask that you provide \$5.79 billion in funding for the NCI in fiscal year 2011—an increase of \$691 million over the fiscal year 2010 appropriation.

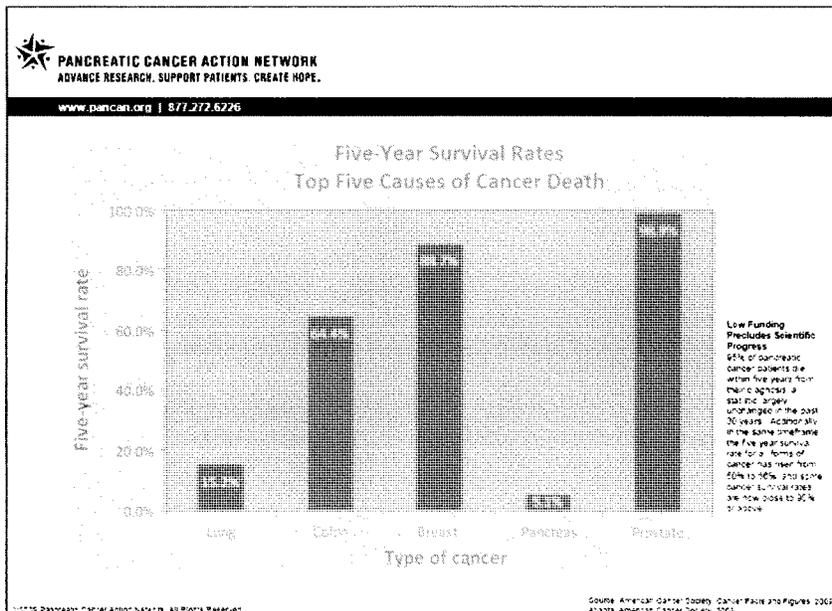
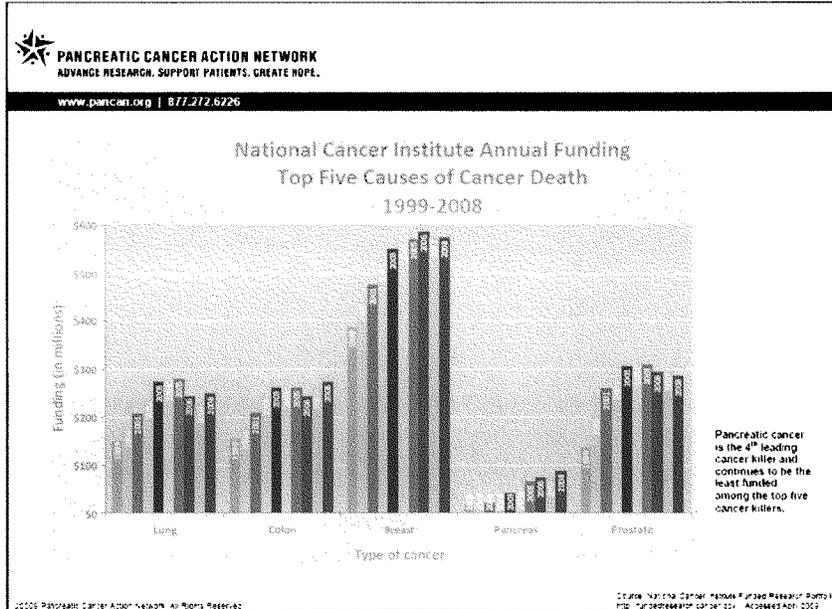
But steps must also be taken to mount a sustainable research effort against pancreatic cancer. Far more resources— money which will attract more scientists—must be brought

to bear in order to find early detection tools and more effective treatments. To those ends, we strongly recommend that:

1. a pancreatic cancer research grant program be established, like the program outlined in the H.R. 745 *The Pancreatic Cancer Research and Education Act*, to support prioritized research projects focused on basic research, finding more precise diagnostic and early detection tools and innovative clinical trials on promising therapeutic agents;
2. a policy of “exceptions” funding for grant applications whose primary focus is on pancreatic cancer needs to be re-instituted at the NCI; and
3. there must be more pancreatic cancer experts included on scientific review panels.

Though the pool of NCI-funded researchers investigating pancreatic cancer has gradually expanded in recent years, it still remains disproportionately miniscule when compared to the number of researchers in the other leading cancer fields. The recommendations I have outlined will help remedy that problem. They will also challenge the research community to rely less on “safe bets” and tackle difficult, high-risk problems, such as pancreatic cancer.

Thank you for your time and consideration.



**Written Testimony Submitted to the House
Labor, Health and Human Services, and Education Appropriations Subcommittee
Regarding FY 2011 Funding for Global Health Research and Development
Christopher J. Elias, MD, MPH
President and CEO, PATH
Tel: 206.285.3500
celias@path.org
April 13, 2010**

PATH appreciates the opportunity to submit written testimony regarding Fiscal Year (FY) 2011 funding for global health research and development to the House Labor, Health and Human Services, and Education Appropriations Subcommittee. PATH is an international nonprofit organization that creates sustainable, culturally relevant solutions, enabling communities worldwide to break longstanding cycles of poor health. By collaborating with diverse public- and private-sector partners, we help provide appropriate health technologies and vital strategies that change the way people think and act.

The ongoing struggle to improve global health relies on the availability of health interventions and technologies designed to prevent, diagnose, and treat disease. Although some effective interventions already exist, many more will be necessary if existing gains against infectious disease and other global health burdens are to be maintained and expanded. The drugs currently available for use against diseases that disproportionately impact the developing world are often too expensive for use in impoverished countries, and are also subject to disease resistance. Vaccines for many of these infectious diseases do not yet exist and diagnostic equipment, vaccine delivery devices, microbicides, contraceptives, and other health technologies appropriate for the developing world are in many cases not available or affordable. Achieving sustainable progress in the struggle to improve global health will require developing new health technologies, and creating or strengthening infrastructures that facilitate their availability to those who need them most.

Such discoveries will require increased funding for global health research and development (R&D). Although the US Government remains one of the most important investors in the development of new technologies, the need overshadows the contribution.

When looking at US spending on R&D writ large over the last four decades, federal spending on all R&D, expressed as a percentage of gross domestic product (GDP), has declined by more than 60 percent: from just under 2 percent of GDP in 1965 to less than 1 percent in 2007.^{*} During a speech delivered in early 2009, President Obama expressed a desire to reverse that trend by requesting a federal R&D budget of \$147.6 billion for fiscal year 2010 and by setting a goal of increasing national investment in R&D to more than 3 percent of GDP.[†] Seizing upon this momentum, in FY 2010 Congress appropriated \$150.4 billion for national research and development—a 2.4 percent increase from 2009 funding. While global health R&D is just one component of the overall national R&D budget, PATH thanks you for this allocation and believes that this is a significant step towards achieving our country's global health goals.

^{*} National Science Foundation. *Gross domestic product and research and development (federally funded, nonfederal, and total): 1953–2007*. Arlington, VA: NSF; 2008. Available at : <http://www.nsf.gov/statistics/nsf08318/pdf/tab13.pdf>

[†] Speech to NAS, April 27, 2009. http://www.whitehouse.gov/the_press_office/Remarks-by-the-President-at-the-National-Academy-of-Sciences-Annual-Meeting/

Robust and sustained R&D funding is crucial to continued global health advancements. Developing a single drug—from basic discovery to clinical testing to product licensure—can cost as much as \$800 million and may take up to a decade.² Developing more complex products may take even longer and be even more expensive—as much as \$1.2 billion.³ R&D costs rise as products advance through clinical testing. In order to test whether a vaccine is safe and effective in humans, for example, researchers require thousands of volunteers and hundreds of health workers. As a result, late-stage trials are typically more expensive to complete than earlier trials.

Effective diagnosis at, or near, the point of care enables better application of available treatment, avoids overuse of antibiotics that can promote resistant strains of pathogens, and allows health care workers to track outbreaks and mobilize resources quickly. Several programs funded in the Labor, Health and Human Services, and Education appropriations bill make a particularly critical contribution to point-of-care diagnostics, a research area that is key to improving health in the developing world. In low-resource settings, where many diagnostic tests are difficult to perform and laboratories are often inaccessible, there is great opportunity to make significant improvements to global health through the development and use of appropriate point-of-care diagnostics. In poor countries, health care facilities can be far away from the widely dispersed populations they serve. Specialized equipment, personnel, and safe waste-disposal systems are often not available. Without diagnostic testing, health care professionals have to rely solely on symptoms to diagnose and treat illness—an imperfect method given the similarity of symptoms among many diseases. This lack of clarity puts individuals, communities, and the world in danger. Incorrect diagnoses can harm people and even cost lives. And from a global perspective, ineffectively treated disease can become a starting point for epidemic or pandemic outbreaks.

The National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) continue to make significant contributions to the development of new health technologies. Generally speaking, NIH carries out the critical basic and preclinical research that provides the foundation for new product discovery and development, supports and conducts clinical trials of promising products, and develops the in-country research capacity of developing world partners. CDC monitors and tracks infectious diseases worldwide, provides those involved in the control and prevention of such diseases with the critical intelligence they need to implement their programs effectively, supports researchers in their work by helping to direct their efforts towards the areas with the greatest potential for benefit, and warns researchers when new trends or disease strains emerge.

Without sufficient funding for NIH and CDC, much of the cutting-edge R&D being performed on point-of-care diagnostics for the developing world would not be taking place. While many commercial and nonprofit groups are working on diagnostic technologies, they are not necessarily doing so with an eye toward the developing world. For example, their efforts often target diseases that mainly concern wealthier countries, or they assume that sophisticated laboratories and trained personnel will be available to complement and operate their diagnostics.

² Conference Report to Accompany H.R. 2997. September 30, 2009.
http://www.rules.house.gov/111/LegText/111_agcr_txt.pdf, p. 84

³ Tufts Center for the Study of Drug Development. Research Milestones. June 19, 2009.

<http://csdd.tufts.edu/Research/Milestones.aspx><http://www.accessdata.fda.gov/scripts/opdlisting/oopd/index.cfm>

In contrast, diagnostic technologies for malaria, enteric diseases, neglected diseases such as Chagas disease, and other conditions whose heaviest burden falls on the developing world do not have a significant commercial market to incentivize research and development. Without investment by the US Government, efforts to develop lower cost, easy to use, and appropriate diagnostic technologies—and by doing so improve care and reduce the development of drug resistance—would be hindered significantly. Expanding funds for these agencies would provide a powerful boost to point-of-care diagnostic development and availability.

One promising area of innovation is nucleic acid (NA) amplification and detection, which is the most accurate way to diagnose many diseases that affect global health. Low-cost, highly accurate tests of this type are usually not available in low-resource settings. The small numbers of centralized laboratories that exist in developing countries tend to be in urban areas and cater primarily to the affluent. In contrast, rural health care facilities commonly have only basic equipment, and health workers have limited training and little ability to maintain equipment and handle reagents. Unreliable electric power to run the tests is also a major obstacle.

Research conducted by PATH with support from NIH and CDC has pointed to the technical feasibility of a new, low-cost, disposable diagnostic platform for NA tests that can be used for detection of a wide variety of infectious diseases, including infant HIV and tuberculosis (TB). Other combinations of diagnostic technologies are also being explored with support from USAID and private funders. Small, portable, low-cost, instrument-free NA amplification tests that do not require electricity would have a vital impact on the ability of health workers and clinicians in developing countries to correctly and quickly diagnose disease. Patients who come from long distances and often cannot wait a few days to receive test results would be able to receive a diagnosis and treatment regimen on site at the point of care. Such tests could potentially replace the need for multi-million dollar central laboratory facilities.

Another area where agencies funded by this Subcommittee are making a significant contribution to global health is the ongoing effort to develop and test malaria vaccines. Malaria is a devastating parasitic disease transmitted through the bite of infected *Anopheles* mosquitoes. More than one-third of the world's population is at risk of malaria, with approximately 250 million cases and one million deaths per year. The vast majority of these deaths occur among African children under the age of five. A malaria vaccine is desperately needed to confront this deadly disease and its impact in the developing world. While consistent use of effective insecticides, insecticide-treated nets, and malaria medicines saves lives, eradicating or even significantly reducing the impact of malaria will require additional interventions, including vaccines. Immunization is one of the most effective health interventions available. Just as it was necessary to use vaccines to control polio and measles in the United States, vaccines are needed as part of an effective control strategy for malaria.

Several federal agencies are involved in R&D for malaria vaccines, in partnership with the PATH Malaria Vaccine Initiative (MVI). NIH supports much of the basic research that underpins malaria drug and vaccine development efforts; the National Institute of Allergy and Infectious Diseases, an institute within NIH, is a particularly central player in malaria vaccine development efforts. CDC performs epidemiological research and international disease surveillance of malaria, providing critical data on the prevalence and spread of each of the four strains of the malaria parasite and the effectiveness of existing interventions.

Indeed, many promising vaccine concepts would never have emerged from the laboratory without the research performed by government scientists. Government-sponsored research is also critical to eliminating from consideration less promising approaches. Due in part to investments by the US Government, there is one malaria vaccine candidate that, if proven, is just five years or so from introduction. In May 2009, RTS,S—developed by GlaxoSmithKline Biologicals—entered a large-scale Phase 3 clinical trial, which is typically one of the final steps before licensure. The trial is being conducted at 11 African study centers in seven countries. Two of the centers, both in Kenya, are partnered with US government agencies, including the CDC and the Walter Reed Army Institute of Research. Results from one Phase 2 clinical study show that RTS,S reduced the risk of clinical malaria by 53 percent in children aged 5 to 17 months. Although this is exciting news, it represents not an end, but a beginning for malaria vaccine development. In order to develop more effective vaccines towards the ultimate goal of eradication, increased investment in research and development at NIH and CDC must continue.

The US Department of Health and Human Services is also using its investments in science and technology to facilitate pandemic influenza preparedness. With support from the Biomedical Advanced Research and Development Authority (BARDA), PATH is supporting the enhancement of sustainable influenza vaccine production capacity in Vietnam as part of global preparedness efforts for a future pandemic. We are collaborating with various partners in Vietnam, including the Government of Vietnam and vaccine manufacturers, to assist in the production and clinical evaluation of affordable, high-quality influenza vaccines. The project builds upon support that BARDA is currently providing to the World Health Organization to assist Vietnam in preparing for eventual licensure and commercial-scale manufacturing of influenza vaccines and is an important step toward increasing local and regional vaccines supplies. This is part of a long-term strategy of international capacity building. As the H1N1 outbreak demonstrated, the emergence of a pandemic strain is unpredictable and the public health response needs are to rapidly create, manufacture, and distribute novel vaccines. Because of global travel and our interconnected world, international cooperation on influenza preparedness has direct relevance for health here in the United States.

Continued progress in our nation's effort to improve global health requires the development of new tools and technologies, which are heavily reliant on research performed and supported by NIH, CDC, and BARDA. For these reasons, we respectfully request robust funding for NIH, CDC, and BARDA to allow the agencies to maximize global health efforts, which each has stated as a priority for FY 2011. Funding for these agencies is critical to moving forward research on HIV/AIDS, TB, malaria, and other diseases which disproportionately impact low-income countries. We support the President's budget request as the minimum amount needed for the Labor, Health and Human Services, and Education account for FY 2011.

We very much appreciate the Subcommittee's consideration of our views, and we stand ready to work with Subcommittee members and staff to ensure continued support for these important issues which are essential to achieving our country's global health goals.



PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS
P-A-N-D-O-R-A
ORGANIZATION FOR RESEARCH AND ADVOCACY *inc.*

April 12, 2010

FROM: Marly Coutinho Silverman, Founder

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TO: House Committee on Appropriations

Subcommittee on Labor, Health and Human Services, Education and Related Agencies
United States House of Representatives - FY 2011

Agencies: DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS) - Secretary of Health Kathy Sebelius - Desired Funding Level: **\$25 million – 5-year funding allocation**

Dear Chair of the Subcommittee on Labor, Health and Human Services and Distinguished Committee Members,

Herein, I present a matter of great importance to our patient advocacy community. It is related to the CFS Advisory Committee (CFSAC), a congressional committee overseen by the Department of Health and Human Services established to provide science-based advice and recommendations to the Secretary of Health and Human Services and the Assistant Secretary for Health on a broad range of issues and topics pertaining to chronic fatigue syndrome (CFS). For 6 years our organization has attended and provided input during CFSAC meetings, and yet not one single crucial recommendation has been implemented or enacted. The current CFSAC charter is due to expire on September 5, 2010. The Committee is governed by the provision of the Federal Advisory Committee Act, as amended (5 U.S.C. Appendix 2), which sets forth standards for the formation and use of advisory committees.

Here, we clearly stress it is a matter of national importance and why it is crucial that this congressional appropriation committee provide funding for research, patient care, physician education, and clinical trial under a DHHS regional centers format. Since September 2005, the CFSAC has consistently, year after year, recommended the following:

September 2004 – Recommendation 1: “We would urge the DHHS to direct the NIH to establish five Centers of Excellence within the United States that would effectively utilize state of the art knowledge concerning the diagnosis, clinical management, treatment, and clinical research for persons with CFS. These Centers should be modeled after the existing Centers of Excellence program, with funding in the range of \$1.5 million per center per year for five years.”

August 2005 – Recommendation 1: “We would urge the DHHS to direct the NIH to establish five Centers of Excellence within the United States that would effectively utilize state-of-the-art knowledge concerning the diagnosis, clinical management, treatment, and clinical research for persons with CFS. These Centers should be modeled after the existing Centers of Excellence program, with funding in the range of \$1.5 million per center per year for five years.”

November 20-21, 2006: The Committee’s **Recommendation 3:** “The committee recommends that CFS be included in the Roadmap Initiative of the NIH.”

May 16-17, 2007–Recommendation 1: “There have been basic scientific advances that should be leading to new treatment strategies, yet progress in translating these advances into effective treatments has been slow. This is due, in large part, to a complete lack of clinical care centers and research centers. Investigators are frustrated by a lack of access to representative patient populations, and patients are frustrated by a lack of accessible expert clinical treatment centers. Funding mechanisms to develop new centers for either clinical care or centers for research are shrinking, but the needs of this underserved, very ill patient population are unmet and growing. Therefore, the CFSAC recommends that the Secretary use the resources and talent of the agencies that make up the HHS to find ways to meet these needs. **One starting point is our request that the HHS establish five regional clinical care, research, and education centers which will to provide offer care to this critically underserved population, educate providers, provide outreach to the, and provide effective basic science as well as translational and clinical research on CFS.** The advisory committee understands that fiscal exigencies have, to date, prevented the formation establishment of these previously recommended centers, but it is our hope that the Secretary will use the full weight of office to effectively fund this program through existing funding mechanisms that might be available or new programs.”

November 28–29, 2007: The CFSAC voted unanimously to send the following recommendations to the Assistant Secretary for Health for transmittal to the Secretary: “It is recommended that a representative of AHRQ be added as an ex officio member of the to CFSAC effective immediately, but at least in advance of the next CFSAC meeting. ... It is recommended that the CDC effort on CFS be restructured to reflect a broader expertise on the multifaceted capabilities required to execute a comprehensive program that incorporates the following elements: 1) an extramural effort directed by the Office of the Director; 2) sufficient funds for a program for which the authority and accountability is housed at the level of a coordinating center director; 3) a lab-based component that maintains the current search for biomarkers and pathophysiology; 4) the recommendations of the external CDC Blue Ribbon panel, including developing, analyzing, and evaluating new interventions and continuing support for longitudinal studies; and 5) an expanded patient, healthcare provider, and family caregiver education effort that is managed by staff with appropriate expertise in clinical and public education strategies.”

May 5–6, 2008: The committee unanimously recommended four items. For the purpose of my testimony I quote: ...“CFSAC recommends to the Secretary of Health and Human Services that the Administrator of HRSA communicate with each Area Health Education

Center (AHEC) regarding the critical need for provider education of CFS. HRSA has the potential to disseminate information on CFS to a wide range of providers, communities, and educational institutions. HRSA should inform these groups that persons with CFS represent an underserved population and that there is a dramatic need for healthcare practitioners who can provide medical services to patients with CFS. HRSA should further inform these groups that the CDC offers a web-based continued education program (CME) on CFS at www.cdc.gov/cfs and encourage AHEC providers to participate in this CME program. Additionally, HRSA should alert AHECs of the availability of a CDC CFS provider toolkit.”

October 28–29, 2008: Several recommendations were made. For the purpose of this testimony, I quote Numbers 1 and 4: “1) It is recommended that DHHS solicit M: COOPERATION BY the Department of Education ~~Cooperation~~ on issues relating to pediatric CFS ... 4) CFSAC recognizes that much can be done to ensure every child with CFS has the best possible access to support and treatments and asks that the Secretary facilitate a taskforce or working group to establish an ongoing interagency and interdepartmental effort to coordinate school, family, financial, and health care support for children and young adults with CFS.

October 29–30, 2009: Recommendation 1: Establish Regional Centers funded by DHHS for clinical care, research, and education on CFS. (Resubmitted from May 2009)

As you can see, year after year the same recommendations are being made, and yet there has not been any progress for the past six years in the most important recommendation from the CFSAC to the Secretary of Health regarding chronic fatigue syndrome: “The establishment of Centers of Excellence or Regional Centers funded by DHHS for clinical care, research, and education on CFS.”

Therefore, we urge you—our congressional leadership—to ensure funding for the Neuroendocrineimmune (NEI) Center,[™] a patient-driven community initiative in the state of New Jersey (and we hope in Florida as well), that will address all of the issues mentioned in the CFSAC recommendations in addition to addressing quality of life issues for patients. We also ask you to provide continuing funding to the Whittemore Peterson Institute for Neuro-Immune Disease (WPI), which is located Reno, Nevada. Please allocate funding for scientific research, clinical trials, patient registry, physician education, public education, and social services to an estimated 20 million Americans stricken with neuroendocrineimmune disorders, such as chronic fatigue syndrome (CFS) and related illnesses. Throughout the U.S., day after day, we witness great suffering being inflicted on individuals, children, teenagers, adults, and the elderly M: IN THE CFS POPULATION.

On February of this year, the North Carolina state Mountain Area Health Education Center (MAHEC) official was put in the awkward position of renegeing on his original agreement to be a CME provider for a pediatric family mini-conference with our organization. The conference included physician training on NEIDS. The MAHEC official

informed us that in an “impromptu meeting with the local Medical Board overseeing the MAHEC programs,” a board comprised of local physicians from the Black Mountain, Asheville, Buncombe County Area expressed that “**In general, they feel the diagnosis and treatment of CFS is a gray area.**” We were told that they felt they should not be involved in training medical providers on NEIDs and much less with our organization. The fact is that, unfortunately, some of the MAHEC physicians were involved in the Baldwin family plight, which involved a child previously diagnosed with CFS and other NEIDs who was taken from his parents after an allegedly and (unconfirmed) anonymous physician report was made to the Buncombe County Department of Social and Senior Services (DSS). It resulted in DSS charges of Munchausen syndrome by proxy leveled against the mother. After a 10-month court case, the judge ruled that the family had “simply failed to provide the minor child with the care of a primary physician.” It is, however, ironic that we can factually state that, as it currently stands in the MAHEC medical system, the MAHEC does not have primary physicians (or any specialists) capable of diagnosing, much less treating, a child with CFS and/or several other NEIDs in the 16 county areas that MAHEC oversees in North Carolina. Our organization spearheaded a nationwide community advocacy outcry. The child is now back with his parents, but during the whole time that the child was shuffled between three foster families during a 9.5-month period, DSS never once provided him with the specialized medical care he needed. The irony is that this particular child had already been approved for Social Security disability due to his illnesses and had access to two electric wheelchairs, which during the court case were taken away from him, placing him at a significant physical risk. I urge you to stand by the side of millions of Americans who presently do not have a voice. Their future depends on your compassion and vision. Help us to restore their health and hopes. This committee has the power. As one of the many individuals stricken with CFS, I thank you for this opportunity to share the plight of so many. We need a hero, and you have the opportunity to demonstrate vision, courage, and foresight by allocating funding for regional centers for clinical care, research, and education for CFS and other neuroendocrineimmune disorders. Thank you!

SUMMARY, BACKGROUND, AND FACTS ON NEUROENDOCRINEIMMUNE DISORDERS

The concept of Neuroendocrineimmune Disorders (NEIDs) applies to illnesses such as chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis or encephalopathy (ME) and also known as chronic fatigue immune deficiency syndrome; fibromyalgia (FM); chronic Lyme disease (CLD); environmental illness (EI); and multiple chemical sensitivity, Alzheimer’s, Lyme disease induced-autism, and Gulf War Illness (GWI). The scientific rationale is that the consistently and well-recorded overlapping of symptoms, medical protocols and biomarkers, indicate that discoveries and advances made in any one of the neuroendocrineimmune illnesses will be applicable and beneficial to other neuroendocrineimmune illnesses, thereby bringing us closer to a cure.

LATEST SCIENTIFIC RESEARCH SUPPORTING THE NEIDS CONCEPT - According to the Whittemore Peterson Institute, "The spectrum of neuro-immune diseases including: Myalgic Encephalomyelitis (ME/CFS), Atypical MS, Fibromyalgia and Gulf War Syndrome, share common abnormalities in the innate immune response, which result in chronic immune activation and immune deficiency. We have detected the retroviral infection XMRV (xenotropic murine leukemia virus-related virus) in greater than 95% of the more than 200 ME/CFS, fibromyalgia, and atypical MS patients tested. The current working hypothesis is that XMRV infection of B, T, NK, and other cells of the innate immune response cause chronic inflammation and immune deficiency, resulting in an inability to mount an effective immune response to opportunistic infections. (See [XMRV paper in Science](#). (DOI: 10.1126/science.1179052). This discovery opens an entirely new avenue of Neuro-Immune Disease related research, and our discovery has brought to this field world-renowned immunologists and retrovirologists building our team of collaborators to translate our discoveries into new treatments as soon as possible. Because retroviruses are known to cause inflammatory diseases, neurological disease, immune deficiency, and cancer, the discovery of XMRV has far-reaching implications for the prevention and treatment of not only lymphoma, one of the potentially devastating complications of ME/CFS, but prostate cancer and perhaps many others."

U.S. BLOOD SUPPLY IS POTENTIALLY TAINTED -Of great urgency to our nation is that the Whittemore Peterson Institute reported that the XMRV virus was also found in 3.7 % of those without CFS, bringing to the forefront the issue that our nation's blood supply is potentially tainted.

POTENTIAL OVERLAPPING OF XMRV WITH CHRONIC LYME DISEASE - According to Dr. Joseph Burrascano, a Lyme disease researcher, the XMRV virus finding has implications for Lyme research because it is possible that patients who carry this virus when co-infected with Lyme go on to have persistent symptoms because a) of activation of the latent virus; b) infection with Lyme or another tick-borne disease lowers the immune surveillance, making the individual more susceptible to "catch" the virus; or c) the presence of the virus and the spirochete together act synergistically to induce an array of illness symptoms or to prevent eradication or control of either organism. In a paper 'Inflammation and central nervous system Lyme disease' published in the journal *Neurobiology of Disease*, Fallon, Hardesty, Levin, and Schweitzer 2009) discussed their finding that neurologic manifestations of Lyme disease occur in 10 to 15% of individuals with untreated Lyme. The researchers discussed the symptoms of neurologic Lyme and reviewed experimental studies that provide insight into the possible mechanisms of inflammation following *Borrelia* infection and contributing risk factors.

DEMOGRAPHICS It is estimated that 20 million Americans are stricken with NEIDs. It crosses barriers of social status, age, and gender. The CDC figures for CFS are now over 4 million Americans. The DOD has stated that 800,000 veterans are stricken with Gulf War illness. It is stated in the CDC website that for Lyme disease "State health departments reported 28,921 confirmed cases and 6,277 probable cases of Lyme disease to CDC in 2008." This represents a 5% increase in confirmed cases since 2007. NIAMS states "Scientists estimate that fibromyalgia affects 5 million Americans 18 or older."

ECONOMIC IMPACT -It is estimated that NEIDs cost our nation \$75 billion annually.



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Testimony of the Pew Center on the States
 Regarding FY2011 Appropriations for the Department of Health and Human Services
 Subcommittee on Labor, Health and Human Services, Education and Related Agencies
 Committee on Appropriations -- United States House of Representatives

Contact Information: Shelly Gehshan
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The Pew Children's Dental Campaign, a campaign of the Pew Center on the States, would like to thank the Subcommittee Chairman for allowing the submission of this testimony in support of fiscal year 2011 appropriations for oral health programs.

The Pew Campaign works primarily at the state level to ensure that more children receive dental care and benefit from policies proven to prevent tooth decay. We are also mounting a national campaign to raise awareness of the problem, recruit influential leaders to call for change, and showcase states that have made progress and can serve as models for pragmatic, cost-effective reform.

The Cost of Delay, recently released by The Pew Center on the States, found that ten years after the 2000 report by the U.S. Surgeon General called dental disease a "silent epidemic," too little has changed. **The report finds that two-thirds of the states are failing to ensure that disadvantaged children get the dental health care they need.** The good news is that this problem can be solved. At a time when state budgets are strapped, children's dental health presents a rare opportunity for federal policy makers to make meaningful investments without breaking the bank—while delivering a strong return to taxpayers.

The consequences of poor dental health among children are far worse—and longer lasting—than most policy makers and the public realize.

- o Early growth and development - Having healthy baby teeth is vital to proper nutrition and speech development and sets the stage for a lifetime of dental health.
- o School readiness and performance - In a single year, more than 51 million hours of school may be missed because of dental-related illness.
- o Overall health - A growing body of research indicates that periodontal disease - gum disease - is linked to cardiovascular disease, diabetes and stroke.
- o Economic consequences - An estimated 164 million work hours each year are lost because of dental disease. Dental problems can hinder a person's ability to get a job in the first place

Adequately funding federal oral health programs will provide critical resources to states to plan, develop, coordinate, and operate cost-effective dental programs that prevent dental disease. Two ongoing federal grant programs housed in the Centers for Disease Control and Prevention and the Human Resources and Services Administration directly support The Pew Campaign's goals, as do several new oral health prevention and workforce programs established by P.L. 111-148 - Patient Protection and Affordable Care Act.

The Pew Center on the States asks that the Subcommittee consider the following FY 2011 funding requests:

Support the expansion of established federal grant programs:

1. CDC State Grants Program, Surveillance, and Technical Assistance - Division of Oral Health

With CDC support, states can better promote oral health and efficiently administer scarce resources, monitor oral health status and problems, and conduct and evaluate prevention programs. This funding is critical to a state's ability to prevent problems before they occur, rather than treating them when they are painful and expensive. These programs also support state community water fluoridation programs and school-based dental sealant programs.

For example, research shows that community water fluoridation offers one of the greatest return-on-investment of any preventive health care strategy. For most cities, every \$1 invested in water fluoridation saves \$38 in dental treatment costs. More than a billion dollars could be saved annually if the remaining water supplies in the United States were fluoridated, according to the Centers for Disease Control.

Pew supports expansion of this grant program to \$33 million per year in order to reach all 50 states and the District of Columbia; an increase of \$18 million over the FY 2010 appropriation.

This program is authorized under Section 4102 of P.L. 111-148 as an amendment to the Public Health Service Act. Funding for this program fits the criteria for uses of the Public Health and Prevention Fund (FY 2011 = \$750 million). **Please recommend and approve the transfer of \$18 million of the Public Health and Prevention Fund to fulfill the program's authorization to support all 50 states.**

2. HRSA Dental Health Improvement Grants

This program provides grants to states to support oral health workforce activities, under Section 340G of the Public Health Service Act, and provide the opportunity for states to implement a range of innovative approaches to improve access to oral health services including, projects that address the oral health workforce needs of underserved areas in both urban and rural locations. For example, Florida used its Human Resources and Services Agency workforce grant for a task force that resulted in a regulatory change to expand the use of hygienists to improve the efficiency of sealant programs. Kansas is using these

resources for several objectives, including promoting extended care permit utilization for dental hygienists and funding loan repayment programs for professionals working in underserved areas among other goals.

Pew supports a grant program that is funded to reach all 50 states and the District of Columbia at a level of \$20 million per year.

Fully fund newly authorized or expanded oral health prevention programs in P.L. 111-148:

3. School-based Sealant Programs - Establishment of school-based dental sealant programs
The law requires that each of the 50 states and territories receive a grant for school-based dental sealant programs as well as to provide funding to Indian tribes. Sealants—clear plastic coatings applied by a hygienist or dentist—cost one-third as much as filling a cavity, and have been shown after just one application to prevent 60 percent of decay in molars. In *The Cost of Delay*, Pew finds that only 17 states have sealant programs that reach even one-quarter of their high-risk schools, and 11 reported having no programs at all.

This program is authorized under Section 4102 of P.L. 111-148 as an amendment to the Public Health Service Act and is an eligible use of funding from the Public Health and Prevention Fund (FY 2011 = \$750 million). **Please recommend and approve the transfer of \$312.5 million of the Public Health and Prevention Fund to fulfill the program authorization to fund all 50 states.** The estimated cost for FY 2011 provides for rapid acceleration and start-up funding along with information technology and evaluation. The annual costs in FY 2013 and beyond should be significantly less as the programs integrate with insurance payment options. **This estimate assumes full funding of the CDC State Grants Program request (above) to support the additional expertise and management necessary for these programs.**

4. Alternative Dental Health Care Providers Demonstration Project
The law establishes/authorizes a five-year, demonstration program beginning within two years of enactment (no later than March 23, 2012) to train or employ alternative dental health care providers in order to increase access to dental health care services in rural and other underserved communities. Each grant shall equal not less than \$4 million (for the life of the project).

Pew requests \$16 million for the first year of this program with at least a two year period of availability. The \$16 million will allow up to four eligible entities to plan and implement a demonstration project funded at \$4 million over the five year project. Pew supports ramping up the appropriations for this program in FY2012 to support additional eligible entities to apply for demonstration projects.

The U.S. Department of Health and Human Services has designated more than 4,000 areas across the country as Dental Health Professional Shortage Areas (DHPSAs). **More than 46 million people live in DHPSAs across the United States, an estimated 30 million of whom lack access to a dentist.**

In 2006, roughly 4,500 new dentists graduated from the United States' 56 dental schools. But it would take more than 6,600 dentists choosing to practice in DHPSAs to provide care for those 30 million people. More than 10 percent of those are needed in Florida alone, where it would take at least 751 new dentists to close the access gap.

These dentist shortages are projected to worsen. Although several dental schools have opened in the past few years, the number of dentists retiring every year will soon exceed the number of new dentists graduating and entering practice. In 2006, more than one-third of all practicing dentists were over the age of 55 and edging toward retirement. The federal expansion of Medicaid and public insurance including dental services will also compound the relative shortage of dentists and further limit access to care. In 2009, Minnesota became the first state in the country to authorize a new primary care dental provider called a dental therapist at both a basic and advanced level. At least twelve states are considering similar models.

5. Oral Healthcare Prevention Education Campaign

The law establishes a 5-year national, public education campaign that is focused on oral healthcare prevention and education. The campaign is required to use science-based strategies to convey oral health prevention messages that include, but are not limited to, community water fluoridation and dental sealants.

This program is authorized under Section 4102 of P.L. 111-148 as an amendment to the Public Health Service Act and is an eligible use of funding from the Public Health and Prevention Fund (FY 2011 = \$750 million). **Please recommend and approve the transfer of \$2 million of the Public Health and Prevention Fund to fulfill the program mandate.** This estimate assumes that planning and testing of messages occurs during FY2011 while the major public education campaign would take place in FY 2012 and beyond.

In total the Pew Center on the States asks the committee to make the following investment in improving oral health for children in the FY2011 budget:

Total FY 2011 request = \$383.5 million

Increase over 2010 appropriations for existing programs = \$351 million

Amount of increase funded by the Prevention and Public Health Fund = \$332.5 million

Increased investment in oral health out of the 302(b) sub-committee budget allocation = \$51 million

By making targeted federal investments in effective policy approaches, states can help eliminate the pain, missed school hours and long-term health and economic consequences of untreated dental disease among kids. A handful of states are leading the way, but all states can and must do more to ensure access to dental care for America's children most in need. Thank you for your consideration of this testimony.

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Dear Members of the House Appropriations Committee:

I would like to take this opportunity to speak up against the idea of a fee-based Voluntary Protection Programs (VPP). As an employee at a VPP site, I believe that this will be detrimental to the integrity of the program and the culture of pro-active safety and health beyond compliance that it currently instills. I would like to tell you that in the short time my plant has been in the VPP, it already nears the 1,000,000 hours work without a loss or restricted-time case. However, the issues of moral and employee welfare pale when compared to the potential downfalls of an industry-funded compliance system.

In his report to the House Budget Committee on March 4, 2010, Congressman George Miller (D-CA), chair of the House Committee on Education and Labor, supported the Department of Labor's (DOL) shift of funding and resources away from VPP in favor of enforcement. He proposed to fund VPP *"through a user fee, and plans to work on establishing authority for augmenting the OSHA budget through a fee based system"*. Funding VPP through a user-fee system for certification would take away from the independent verification of our safety and health management system because it would lead to a direct relationship between number of VPP sites and fees paid to the government. Some repeated concerns expressed by many of our 921,000 American workers now covered by VPP include:

- Industry directly funding the government to perform part of its required function under the OSH Act.
- Creating the perception that employers are "buying" the VPP flag.
- Creating a situation where employers can be perceived as purchasing "an exemption from routine OSHA inspections."
- Fees for VPP deterring small businesses from participating.
- Charging sites for participation in VPP despite of what VPP sites voluntarily give in the form of mentoring, outreach, assist visits, funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national conferences.
- Paying a fee reduces VPP to a government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride.

In a way, America's worksites would be directly funding the Occupational Safety and Health Administration (OSHA) to perform its functions as required by the OSH Act and private industry

and special interests' funding the Federal Government is against the law. The Occupational Safety and Health Act of 1970 requires 13 objectives to be accomplished. Only **one** of the 13 objectives is enforcement, **two** are standard setting, and **three** are directly related to the development of cooperation between employer and employee to establish a safe workplace – exactly what the founders of OSHA VPP established the program to accomplish. Congress and DOL taking actions to shift funding from VPP in favor of enforcement is not a return to OSHA's 'roots in enforcement,' only an Agency ignoring 12 other mandates from Congress and asking American's worksites to provide that funding through a user fee-based system to pay the agency to implement all the requirements under the OSH Act.

Unlike many fee-based certification programs, VPP is a comprehensive workplace safety and health management system that is built on cooperation among workers, employers and government. If the DOL backs away from the partnership, it diminishes the program instead of strengthening OSHA's partnership with corporate America in an effort to push beyond outdated standards.

While I continue to support firm and fair enforcement as a necessary tool to reach worksites that are not voluntarily improving their safety and health programs, I firmly believe that there is clear evidence that 40 years of enforcement has failed in producing the necessary culture shift that is required to achieve measurable and sustainable improvements in the protection of the American workforce and to keep American businesses competitive in a global marketplace.

It is clear that 40 years of enforcement have left American's small businesses - collectively the largest employers and source of future "*good jobs*" – lacking. Under any administration, OSHA's dealings with America's small businesses has either been '*hands-off*' or "*penalize to closure*," because those are the only two options in an Agency focusing solely on enforcement. In recent years, smaller worksites have increased significantly within VPP, growing from 28 percent of VPP sites in 2003 to 39 percent in 2008, thanks to innovations such as mentoring and the VPP Challenge Program. These innovations are keeping employees safer at worksites that traditionally would not see an OSHA compliance inspection or, if fined, might have to go out of business or at the very least provide lay-off notices to employees to cover the citation and associated penalties. These worksites have seen the value in a proactive safety program, such as VPP, that is saving companies and taxpayers money.

In 2007, OSHA evaluated the benefits of the VPP and reported that Federal Agency VPP participants, in OSHA, the Department of Energy (DOE), the Department of Defense (DOD), and the National Parks Service, to name a few, saved the government more than \$59 million by avoiding injuries and the private sector VPP participants saved more than \$300 million. These funds are a return on investment that are funneled into new equipment, expanding production, creating '*good jobs*,' keeping '*good jobs*,' and voluntarily mentoring other work sites in the community to learn the value of VPP and keeping American workers safe. That money should not be used to fund the Federal Government to perform its required obligations under the OSH Act.

The Federal Government already benefits from its involvement in VPP and from the private sector's participation in VPP, such as:

- The \$59 million saved by Federal Agency participants in VPP is money that demonstrates fiscal responsibility and cost avoidance and allows for the reallocation of resources to the mission of the Agency.
- The U.S. Department of Labor's Safety, Health, and Return-to-Employment (SHARE) initiative was launched in 2004 to help the Federal Government in reducing injury and illness cases and lost production day rates, and to substantially improve timely filing of injury and illness notices. Agencies that adopted VPP achieved greater and sustainable improved performance in the SHARE initiative and want to expand the VPP throughout their operations.
- The DOD, with 31 VPP sites, has seen a substantial return on investment by adopting VPP in terms of reduced injuries and illnesses and a strong improvement in maintaining mission-readiness.
- In 2003, the DOE Appropriations language noted a dramatic improvement in the safety and health within the Complex and challenged DOE to "*maintain worker safety and health performance at least to levels seen in 2002,*" that performance was achieved by 21 VPP sites in the DOE Complex.
- The cost avoidance in workers compensation for a single contractor in the DOE Complex was a \$3 million cost reduction in three years by working toward and installing VPP. That was \$3 million in taxpayers' money redirected to the DOE mission, just by preventing worker injuries.
- OSHA also directly benefits by reducing employee injuries and illnesses at three of its Regional Field Offices that are VPP.
- Additionally, when workplaces make the significant commitment to safety required by VPP, it allows OSHA to focus its resources of enforcement where they are most needed – on those companies that "*don't get it*" – as stated by the Secretary of Labor.

Recent tragic events in the American workplace cause us great concern, such as the mining disaster in West Virginia and the refinery explosion in Washington state. These events remind us that when we continue to return to only one tool in OSHA's toolbox to achieve a safe workplace – and that tool is enforcement – that we will never achieve, as a nation, the necessary culture, mindset and attributes necessary to protect our most valued asset – the American worker. Each of these tragic examples, worksites and employers had received routine inspections and citations from OSHA and the Mine Safety & Health Administration (MSHA) compliance officers. Those visits were routine, on average five inspections in the past seven years, all with citations and large fines. These events demonstrate what 40 years of enforcement have achieved; and why would recapitulating this lesson return different results? Would more workers go home to their families at night?

Instead, what if on just one of those OSHA or MSHA inspections the compliance officer would have recommended the company enter into the VPP Challenge Program?

- *What if*, through OSHA's VPP, one of those companies had learned the value, in human preservation and financially, of preventing accidents and avoiding costs and impacts to the bottom line?
- *What if* one of those companies was the first in their industry to demonstrate that safety and profitability are achievable together?
- *What if* others in their industry took notice and started to embrace the same ideas and sought to achieve VPP status in order to maintain a competitive edge?

Would more workers then go home to their families at night?

I ask you to speak out against the idea of a fee-based Voluntary Protection Programs and to ensure the continued success of OSHA's VPP as a cooperative program by reinstating direct and continued funding in the DOL budget. Highly successful cooperative programs like VPP should be funded and expanded if OSHA is to assist American businesses in achieving the necessary cultural change required to maintain and protect American workers, which is a proven method that supports OSHA's mission. I ask that you provide full funding in the DOL budget for VPP and include specific Appropriations language to restore and direct the Agency to fund, resource load and conduct VPP assistance, application evaluations, onsite re-approvals and new onsite evaluations to the levels equal to or greater than those achieved in 2005.

Sincerely,

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Fiscal Year 2011 Appropriations
Submitted by: Athena Abdullah, JD, Director, Government Relations, PAEA
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TESTIMONY OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION
SUBMITTED TO THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,
AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS
UNITED STATES HOUSE OF REPRESENTATIVES
REGARDING FISCAL YEAR 2011 APPROPRIATIONS

April 15, 2010

On behalf of its membership, the 149 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit these comments on the fiscal year (FY) 2011 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act.

PAEA is a member of the Health Professions and Nursing Education Coalition (HPNEC) and we support the HPNEC recommendation for funding of at least \$600 million in FY 2011 for the health professions education programs authorized under Title VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA).

PAEA is grateful to the Subcommittee for the recent funding increases for Title VII Health Professions programs in the Consolidated Appropriations Act, 2010 (P.L. 111-117) and for your support of Title VII health professions programs.

Need for Increased Federal Funding

Faculty development is one of the profession's critical needs. In order to attract the best qualified to teaching, PA education programs must have the resources to train faculty in academic skills, such as curriculum development, teaching methods, and laboratory instruction. The challenges of teaching are broad and varied and include understanding different pedagogical theories, writing instructional objectives, and learning and applying educational technology. Most educators come from clinical practice and these skills are essential to transitioning to teaching. Educators are a critical element of meeting the nation's demand for an increased supply of primary care clinicians.

Generalist training, workforce diversity, and practice in underserved areas are key priorities identified by HRSA. It is increasingly important that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in health care. PA programs have been successful in attracting students from underrepresented minority groups

and disadvantaged backgrounds. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care.

Physician Assistant Practice

Physician assistants (PAs) are licensed health professionals who practice medicine as members of a team with their supervising physicians. PAs exercise autonomy in medical decision making and provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings. In all 50 states, PAs carry out physician-delegated duties that are allowed by law and within the physician's scope of practice and the PA's training and experience. Additionally, PAs are delegated prescriptive privileges by their physician supervisors in all 50 states, the District of Columbia, and Guam. This allows PAs to practice in rural, medically underserved areas where they are often the only full-time medical provider.

Physician Assistant Education

There are currently 149 accredited PA education programs in the United States, which together graduate nearly 6,000 PA students each year. PAs are educated as generalists in medicine; their flexibility allows them to practice in more than 60 medical and surgical specialties. More than one-third of PA program graduates practice in primary care.

The average PA education program is 27 months in length. Typically, one year is devoted to classroom study and approximately 15 months is devoted to clinical rotations. The typical curriculum includes 400 hours of basic sciences and nearly 600 hours of clinical medicine.

The profession is expected to continue to grow as a result of the projected shortage of physicians and other health care professionals, the growing demand for professionals from an aging population, and the continuing strong PA applicant pool, which has grown by more than 10 percent each year since the year 2000. The Bureau of Labor Statistics projects a 39% increase in the number of PA jobs between 2008 and 2018. With its relatively short initial training time and the flexibility of generalist-trained PAs, the PA profession is well-positioned to help fill projected shortages in the numbers of health care professionals.

Currently there are almost twenty new PA programs in the accreditation pipeline. The continued growth of the profession heightens the need for additional resources. Additional resources will help meet the challenges of recruiting qualified faculty, shortages of preceptors and clinical sites, and the need to continue our work to increase the diversity of faculty and program applicants.

Title VII Funding

Title VII funding is the only opportunity for PA programs to apply for federal funding and plays a crucial role in developing and supporting PA education programs.

Title VII funding fills a critical need for curriculum development and faculty development. Funding enhances clinical training and education, assists PA programs with recruiting applicants from minority and disadvantaged backgrounds, and funds innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA

students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients in underserved areas.

Title VII support for PA programs has been strengthened with the enactment of the Patient Protection and Affordable Health Care Act (P.L. 111-148), which provides a 15 percent carve out in the appropriations process for PA programs. This funding will enhance capabilities to train a growing PA workforce and is likely to increase the applicant pool for faculty positions as a result of PA programs now being eligible for faculty loan repayment. Huge loan burdens serve as barriers for PAs' entry into academia.

Here we provide several examples of how PA programs have used Title VII funds to creatively expand care to underserved areas and populations, as well as to develop a diverse PA workforce.

- One Texas program has used its PA training grant to support the program at a distant site in an underserved area. This grant provides assistance to the program for recruiting, educating, and training PA students in the largely Hispanic South Texas and mid-Texas/Mexico border areas and supports new faculty development.
- A Utah program has used its PA training grant to promote interprofessional teams — an area of strong emphasis in the Patient Protection and Affordable Care Act — by creating a model geriatric curriculum that includes didactic and clinical education. The grant has also allowed the program to optimize its relationship with three service-learning partners and develop new partnerships with three service-learning sites.
- An Alabama program used its PA training grant to update and expand the current health behavior educational curriculum and HIV/STD training. They were also able to include PA students from other programs who were interested in rural, primary care medicine for a four-week comprehensive educational program in HIV disease diagnosis and management.
- A South Carolina program has developed a model program that offers a two-year academic fellowship for recent PA graduates with at least one year of clinical experience. To further enhance an evidence-based approach to education and practice, two specific evidence-based practice projects were embedded in the fellowship experience. Fellows direct and evaluate PA students' involvement in the "Towards No Tobacco" curriculum, aimed at fifth graders, and the PDA Patient Data experience, aimed at assessing health care services.

Recommendations on FY 2011 Funding

The Physician Assistant Education Association requests the Appropriations Committee to support funding for Title VII and VIII health professions programs at a minimum of \$600 million for FY 2011. This level of funding is crucial to support the nation's demand for primary care practitioners, particularly those who will practice in medically underserved areas and serve vulnerable populations. Additionally we encourage support for the new programs and responsibilities contained in the Patient Protection and Affordable Care Act (P.L. 111-148), including a minimum of \$10 million to support PA education programs. We thank the members of the subcommittee for their continued support of the health professions and look forward to

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your continued support of solutions to the nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's FY 2011 funding recommendation.



Testimony submitted to the
U.S. House of Representatives Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Addressing the National Institutes of Health (NIH)

April 12, 2010

Submitted by:

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Mr. Chairman, Ranking Member and Members of the Subcommittee:

Thank you for the opportunity to provide testimony on behalf of the PKD Foundation and the more than 600,000 Americans and 12.5 million people world-wide suffering from polycystic kidney disease (PKD). This Subcommittee's commitment to advancing the great work of the National Institutes of Health (NIH) is legendary, and it must be continued. To meet that need, the PKD Foundation supports funding NIH at \$35 billion in FY 2011. Underfunding NIH will only slow the pace and progress of scientific discoveries for PKD patients and all people living with a life-threatening disease or chronic condition.

The PKD Foundation also supports an appropriation of \$500 million to the newly authorized Cures Acceleration Network as established under the Patient Protection and Affordable Care Act (P.L. 11-148; Title X: Sec. 10409.). In order to help bridge the biomedical research "valley of death," CAN and other innovative initiatives aimed at improving translational research and regulatory science at NIH must be fully funded.

PKD Essentials

Polycystic kidney disease or PKD is one of the world's most prevalent, life-threatening, genetic diseases affecting more than 600,000 Americans including newborns, children and adults regardless of gender, age, race or ethnicity. With the presence of PKD, cysts develop in both kidneys, leading to an increase in kidney size and weight. Cysts can range in size from a pinhead to a grapefruit or a football. They may also cause a normal kidney to grow from the size of a person's fist to that of a football or a basketball and weigh as much as 38 pounds each. Early in



the disease, patients often do not experience symptoms and many do not realize they have PKD until other organs become affected. Deterioration in every PKD patient varies, but ultimately more than half will end up in renal failure and require dialysis or a kidney transplant. Currently, there is no treatment or cure for PKD.

PKD Research Today

PKD is the most therapy-ripe of all kidney diseases; research in PKD is progressive and robust. According to Dr. Francis Collins, NIH Director and former director of the Human Genome Research Institute, PKD research offers a tremendous "return on investment." Dr. Collins called "PKD [is] one of the hottest, most promising areas of research in all of biochemistry." In 1994, scientists discovered the genes that cause PKD, and currently, more than 20 clinical trials are underway to help uncover a treatment.

Even with such success, PKD research is at a critical juncture. Akin to other diseases and chronic conditions, PKD researchers, patients and families are facing the biomedical research "valley of death," the chasm in which basic research can languish. The "valley of death" is the point in the drug development pipeline where scientists work to develop prototype designs or invest in preclinical development. Because these processes are risky, funding is inconsistent and good ideas are often stopped in their tracks. The PKD Foundation seeks to overcome this chasm by developing systems to help advance and investing in translational research.

The PKD Foundation believes there are three components necessary for bridging the "valley of death." Those include: 1) purpose driven research with milestone gated research targets; 2) catalyzing and de-risking the drug development process to help encourage pharmaceutical and biotechnology companies and major donors to invest; and, 3) mobilizing impatient patients who will not accept the status quo.

Efforts to Bridge the "Valley of Death"

On February 24, 2010, the NIH and the Food and Drug Administration (FDA) announced a collaborative initiative aimed at accelerating the drug development process by helping translate basic science into the availability of new and innovative drugs and devices. The NIH-FDA Initiative involves two interrelated scientific disciplines: translational research and regulatory science. Translational research involves shaping basic scientific discoveries into potential treatments. Regulatory science focuses on developing and using tools and standards to more efficiently aid in the development of therapeutic products. Improved regulatory science will help the FDA more effectively evaluate products for their safety and efficacy and help NIH scientists better understand what types of data and information should be collected for advancing basic research through the drug development process.



The PKD Foundation fully supports this initiative and applauds the Department of Health and Human Services (HHS) for taking a bold step in addressing a lagging component in the drug development process. Both translational research and regulatory science are imperative for turning basic biomedical discoveries into therapies that will improve the health and well-being of patients. Providing a platform for purpose driven research is a necessary step in building a bridge over the "valley of death."

In addition to the NIH-FDA Initiative on translational and regulatory science, the PKD Foundation applauds Congress for authorizing the Cures Acceleration Network (CAN) through the Patient Protection and Affordable Care Act. Housed within the Office of the Director of NIH, CAN will work to bridge the "valley of death" by helping identify and advance basic research via translational scientific discoveries through a new grant making system.

The PKD Foundation is confident that the role and programmatic functions of CAN will help address the unmet needs of our impatient patients. We are optimistic that CAN will help catalyze and de-risk the drug development process, thereby encouraging pharmaceutical and biotechnology companies to reach back and invest in developing safe and effective therapies. In order to realize the great potential of CAN, the PKD Foundation urges the Subcommittee to fund CAN at its \$500 million authorizing level.

Conclusion

The NIH-FDA Initiative on translational and regulatory science and the Cures Acceleration Network are innovative ideas aimed at bridging the biomedical research "valley of death." Coupling these innovative public endeavors with the efforts of private entities, such as the PKD Foundation's Drug Discovery Project, should help PKD patients and families rest a bit easier. Together we are working to advance the basic science and understanding of PKD, speed the discovery of treatments, and perhaps one day find a cure for PKD. To that end, the PKD Foundation supports \$35 billion for NIH in FY 2011 and \$500 million for the Cures Acceleration Network. Funding NIH and its important initiatives and programs is one key to the future success of PKD research. Thank you.

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Testimony on behalf of the
Population Association of America/Association of Population Centers
Regarding the Fiscal Year 2011 Appropriation for the
**National Institutes of Health, National Center for Health Statistics and Bureau of Labor
Statistics**

Submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
The Honorable David Obey, Chairman

Submitted by
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Introduction

Thank you, Mr. Chairman Obey, Ranking Member Tiahrt, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH), the National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS).

Background on the PAA/APC and Demographic Research

The Population Association of America (PAA) is a scientific organization comprised of over 3,000 population research professionals, including demographers, sociologists, statisticians, and economists. The Association of Population Centers (APC) is a similar organization comprised of over 30 universities and research groups that foster collaborative demographic research and data sharing, translate basic population research for policy makers, and provide educational and training opportunities in population studies. Over 40 population research centers are located nationwide, including the University of Wisconsin-Madison, State University New York Albany, Brown University, Ohio State University, University of California at Los Angeles, University of North Carolina-Chapel Hill, and Pennsylvania State University.

Demography is the study of populations and how or why they change. Demographers, as well as other population researchers, collect and analyze data on trends in births, deaths, and disabilities as well as racial, ethnic, and socioeconomic changes in populations. Major policy issues population researchers are studying include the demographic causes and consequences of population aging, trends in fertility, marriage, and divorce and their effects on the health and well being of children, and immigration and migration and how changes in these patterns affect the ethnic and cultural diversity of our population and the nation's health and environment.

The NIH mission is to support research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, the NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD).

National Institute on Aging

According to the Census Bureau, by 2029, all of the baby boomers (those born between 1946 and 1964) will be age 65 years and over. As a result, the population age 65–74 years will increase from 6% to 10% of the total population between 2005 and 2030. This substantial growth in the older population is driving policymakers to consider dramatic changes in federal entitlement programs, such as Medicare and Social Security, and other budgetary changes that could affect programs serving the elderly. To inform this debate, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, and health characteristics of the older population. The NIA Division of Behavioral and Social Research (BSR) is the primary source of federal support for basic research on these topics.

In addition to supporting an impressive research portfolio, that includes the prestigious Centers of Demography of Aging Program, the NIA BSR program also supports several large, accessible data surveys. One of these surveys, the Health and Retirement Study (HRS), has become one of the seminal sources of information to assess the health and socioeconomic status of older people in the U.S. The HRS, now entering its 18th year, has tracked 27,000 people, and has provided data on a number of issues, including the role families play in the provision of resources to needy elderly and the economic and health consequences of a spouse's death. The Social Security Administration recognizes and funds the HRS as one of its "Research Partners" and posts the study on its home page to improve its availability to the public and policymakers. HRS is particularly valuable because its longitudinal design allows researchers: 1) the ability to immediately study the impact of important policy changes, such as Medicare Part D; and 2) the opportunity to gain insight into future health-related policy issues that may be on the horizon, such as recent HRS data indicating an increase in pre-retirees self-reported rates of disability. HRS is now collecting DNA, enhancing its value as an important source of biosocial data.

In FY 2010, NIA made awards, expanding its Roybal Centers for Translational Research in the Behavioral and Social Sciences of Aging program to 13 centers and its Demography of Aging Centers program to 14 centers. Fiscal Year 2011 is important year for these centers, which are poised to make significant contributions towards improving the health and well being of older people. With additional support in FY 2011, the NIA BSR program could fully fund its existing centers and support its ongoing surveys without enacting draconian cost cutting measures, such as cutting sample size. Additional support would allow NIA to expand the centers' role in understanding the domestic macroeconomic as well as the global competitiveness impact of population aging. NIA could also use additional resources to support individual investigator awards by precluding an 18% cut in competing awards, improving its funding pipeline, currently at the ninth percentile, and sustaining training and research opportunities for new investigators.

National Institute on Child Health and Human Development

Since its establishment in 1968, the NICHD Center for Population Research has supported research on population processes and change. Today, this research is housed in the Center's Demographic and Behavioral Sciences Branch (DBSB). The Branch encompasses research in four broad areas: family and fertility, mortality and health, migration and population distribution, and population composition. In addition to funding research projects in these areas, DBSB also supports a highly regarded population research infrastructure program and a number of large database studies, including the Fragile Families and Child Well Being Study and National Longitudinal Study of Adolescent Health.

NIH-funded demographic research has consistently provided critical scientific knowledge on issues of greatest consequence for American families: work-family conflicts, marriage and childbearing, childcare, and family and household behavior. However, in the realm of public health, demographic research is having an even larger impact, particularly on issues regarding adolescent and minority health. Understanding the role of marriage and stable families in the health and development of children is another major focus of the NICHD DBSB. Consistently, research has shown children raised in stable family environments have positive health and development outcomes. Policymakers and community programs can use these findings to support unstable families and improve the health and well being of children.

In 2007, the DBSB issued a revised five-year strategic plan, *Future Directions for the DBSB*. With the help of its expert panel and with input from others inside and outside of the agency, the Branch identified three important research areas, family formation, causes and consequences for population health, and the effects of migration, for focus during the 2007 through 2011 period. In addition to these areas of emphasis, the Branch will continue to develop and support other areas within its portfolio, including research on HIV/AIDS, unintended pregnancy and infertility, race and ethnicity, and population and environment. Although the field is enthusiastic about the opportunities the revised strategic research plan presents, we recognize the Institute needs consistent, sufficient funding to realize its potential.

With additional support in FY 2011, NICHD could fully fund its large-scale surveys, which serve as a resource for researchers nationwide. Furthermore, the Institute could apply additional resources toward improving its funding pipeline. Additional support could be used to preclude cuts of 17% to 22% in applications approved for funding and to support and stabilize essential training and career development programs necessary to prepare the next generation of researchers.

National Center for Health Statistics

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System, which contracts with the states to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey, National Health Interview Survey, and National Survey of

Family Growth. Together, NCHS programs provide credible data necessary to answer basic questions about the state of our nation's health.

The President's FY 2011 budget requests \$161.8 million in program funds for NCHS. This recommendation represents an increase of \$23 million over FY 2008. Although it may sound generous, this increase is absolutely essential for stabilizing the agency and its key operations. Before Congress and the Administration began steadily increasing the agency's budget in 2008, NCHS had lost \$13 million in purchasing power between FY 2005 and FY 2007 due to years of flat funding and inflation. These shortfalls forced the elimination of some data collection and quality control efforts, threatened the collection of vital statistics, stymied the adoption of electronic systems, and limited the agency's ability to modernize surveys to reflect changes in demography, geography, and changes in health delivery.

The Administration's FY 2011 request allows NCHS to move beyond restoration of operations and begin repairing services. Specifically, the agency could initiate web-based electronic birth registration in 6 states and 4 territories and phase in electronic death registration in 50/50 cost sharing mechanism with the states. The NHIS sample could be increased from 35,000 to 43,000 households, providing much needed state and community level data and information about smaller racial/ethnic populations.

Bureau of Labor Statistics

The Bureau of Labor Statistics (BLS) provides data used extensively by researchers who study time use, work-family conflicts, labor force dynamics and economic trends. PAA and APC support the agency's proposal to modernize the Consumer Expenditure Survey and improve the Consumer Price Index survey. We support the additional \$2.5 million BLS is requesting to develop a supplemental statistical poverty measure in conjunction with the Census Bureau.

Summary of Recommendations

PAA and APC are pleased the Administration requested \$32 billion for NIH in FY 2011. Although this funding would give NIH a \$1 billion, an inflationary increase, it is not enough to sustain the capacity generated by the infusion of funds from the American Recovery and Reinvestment Act (ARRA). Thus, we endorse the Ad Hoc Group for Medical Research's call for \$35 billion in FY 2011.

PAA and APC, as members of the Friends of NCHS, support a FY 2011 appropriation of \$ 161.8 million, a \$23 million increase , for the NCHS. This funding is needed to maintain the nation's vital statistics system and to update the agency's major health survey operations.

PAA and APC also support the Administration's request for the BLS, \$645.4 million.

Thank you for considering our requests and for supporting federal programs that benefit the field of population research.

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April 16, 2010

Reference: Support for OSHA VPP (Voluntary Protection Program)

To: The Members of the House Appropriation Committee

I have been an employee of this site since 1980. Our site has been an OSHA STAR site since 1996. I have seen firsthand the positive impact that VPP can have on a safety program, and more importantly on the safety of employees in the field. I am asking for Congress to fully fund the VPP program to support worker safety.

Sincerely,

Burt Taylor
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Prevent Blindness America
Written Testimony to the Senate Appropriations
Labor, Health and Human Services, Education,
and Related Agencies Subcommittee
Submitted by: Hugh Parry, President & CEO, Prevent Blindness America
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April 16, 2010

Funding Request Overview

Prevent Blindness America appreciates the opportunity to submit written testimony for the record regarding fiscal year (FY) 2011 funding for vision related programs. As the nation's leading non-profit, voluntary organization dedicated to preventing blindness and preserving sight, Prevent Blindness America maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight. Prevent Blindness America respectfully requests that the Subcommittee provide the following allocations in FY 2011 to help promote eye health and prevent eye disease and vision loss:

- \$5 million for the Vision Health Initiative at the Centers for Disease Control and Prevention (CDC);
- \$1.2 million in FY 2011 to support the Maternal and Child Health Bureau's (MCHB) National Universal Vision Screening for Young Children's Coordinating Center (Center);
- \$730 million in FY 2011 for the Title V Maternal and Child Health (MCH) Services Block Grant; and
- Increased FY 2011 funding for the National Eye Institute (NEI).

Introduction and Overview

Vision-related conditions affect people across the lifespan from childhood through elder years. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to ten percent of preschool age children. Vision disorders (including amblyopia ("lazy eye"), strabismus ("cross eye"), and refractive error) are the leading cause of impaired health in childhood.

Of serious concern is that the NEI reports "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."¹ Among Americans age 40 and older, the four most common eye diseases causing vision impairment and blindness are age-related macular degeneration (AMD), cataract, diabetic retinopathy, and glaucoma.² Refractive errors are the most frequent vision problem in the U.S. – an estimated 150 million Americans use corrective eyewear to compensate for their refractive

¹ "Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America," Prevent Blindness America and the National Eye Institute, 2008.

² Ibid.

error.³ Uncorrected or under-corrected refractive error can result in significant vision impairment.⁴

While half of all blindness can be prevented through education, early detection, and treatment, it is estimated that the number of blind and visually impaired people will double by 2030, if nothing is done to curb vision problems. To curtail the increasing incidence of vision loss in America, Prevent Blindness America advocates sustained and meaningful federal funding for: programs that help promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. We thank the Subcommittee for its consideration of our specific FY 2011 funding requests, which are detailed below.

CDC's Vision Health Initiative: Helping to Save Sight and Save Money

The financial costs of vision impairment to our country's fiscal health are staggering. Prevent Blindness America estimates that the annual costs of adult vision problems in the U.S. are approximately \$51.4 billion.⁵ The annual cost of untreated amblyopia – reduced vision in an eye that has not received adequate use during early childhood – is approximately \$7.4 billion in lost productivity.⁶ NEI estimates that in 2003 the total direct and indirect costs of visual disorders and disabilities in the U.S. were approximately \$68 billion dollars, and with each passing year these costs continue to escalate.⁷ Vision care services consistently have been found to help prevent blindness, reduce vision loss, improve quality of life and well-being, increase productivity, and reduce costs and burdens on the nation's health care system. Therefore, the nation must increase access to – and awareness of the importance of – vision screenings and linkage to appropriate care for at-risk and underserved populations, as is provided by the CDC's Vision Health Initiative.

The CDC reports that “vision disability is one of the top ten disabilities among adults 18 years and older and the single most prevalent disabling condition among children.”⁸ Effective public health initiatives can dramatically decrease the number of Americans who have vision loss or low vision. Initially funded by Congress in FY 2003, the CDC's Vision Health Initiative has worked in a cost-effective way to identify, screen, and link to appropriate care individuals at risk for vision loss. This public-private partnership combines the resources of the CDC, chronic disease directors, state and local Agencies on Aging, and non-profit organizations such as Prevent Blindness America. Highlights of the significant work of the CDC's Vision Health Initiative include:

- ✓ Supporting the eye evaluation component of the National Health and Nutrition Examination Survey (NHANES) that provides current, nationally representative data and helps assess

³ Ibid

⁴ Ibid.

⁵ “The Economic Impact of Vision Problems,” Prevent Blindness America, 2007.

⁶ “Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health,” Prevent Blindness America,” Prevent Blindness America, 2008.

⁷ Ellwein Leon. Updating the Hu 1981 Estimates of the Economic Costs of Visual Disorders and Disabilities.

⁸ “Improving the Nation's Vision Health: A Coordinated Public Health Approach,” Centers for Disease Control, 2006.

progress for vision objectives contained within Healthy People 2010 and the future efforts for Healthy People 2020.

- ✓ Utilizing applied public health research to address the economic costs of vision disorders and develop cost-effectiveness models for eye diseases among various populations. Estimating the true economic burden is essential for informing policymakers and for obtaining necessary resources to develop and implement effective interventions.
- ✓ Aiding in the translation of science into programs, services, and policies and in coordinating service activities with partners in the public, private, and voluntary sectors.
 - Under the leadership of researchers at Johns Hopkins University investigating the best methods for identifying patients who need eye care services and providing linkages to follow-up care within community health centers.
 - In coordination with researchers at Duke University evaluation of strategies in primary care and pediatric settings to improve the detection of childhood vision conditions and diseases.
- ✓ Providing data analyses and a systematic review of interventions to promote screening for diabetic retinopathy and reviewing access to and utilization of vision care in the United States.
 - ✓ Developing the first optional Behavioral Risk Factor Surveillance System (BRFSS) vision module and introducing it into state use in 2005 to gather information about access to eye care and prevalence of eye disease and eye injury. Five states implemented the module in 2005, and 11 states began using the module in 2006.

In FY 2010, Prevent Blindness America requested \$4.5 million to sustain and expand the Vision Health Initiative. In the final FY 2010 Consolidated Appropriations Act, Congress allocated \$3.229 million a \$7,000 increase from FY 2009. Prevent Blindness America understands the budgetary challenges facing Congress and the nation and, as such, appreciates this much-needed funding. However, with the demographics of eye disease, we strongly feel that a greater investment in the Vision Health Initiative must be made, so we can mount an adequate effort to address the growing public health threat of preventable vision loss among older Americans, low-income, and underserved populations.

To that end, Prevent Blindness America respectfully requests the Subcommittee provide a \$5 million allocation for the Vision Health Initiative. This level of investment will help the CDC sustain and expand its efforts to address the growing public health threat of preventable vision loss among at-risk and underserved populations. Additional FY 2011 resources will support: strengthen state-based public health efforts to address vision and eye health; development of additional evidence-based public health interventions that improve eye health among the nation's most at-risk and underserved; and expand initiatives to address the growing problem of diabetes among children and the associated impacts of diabetic retinopathy, which can develop later in life.

Investing in the Vision of Our Nation's Most Valuable Resource – Children

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern, due to the fact that, if left untreated, they can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Although more than 12.1 million school-age children have some form of a vision problem, only one-third of all children receive eye care services before the age of six.⁹ Approximately 80 percent of what a child learns is done so visually.¹⁰ As such, good vision is essential for educational progress, proper physical development and athletic performance, and healthy self-esteem in growing children. Yet, according to a CDC report, only one in three children in America has received eye care services before the age of six.

In 2009, the Maternal and Child Health Bureau created the National Universal Vision Screening for Young Children Coordinating Center, a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children. Prevent Blindness America is requesting \$1.2 million in FY 2011 for the National Universal Vision Screening for Young Children Coordinating Center.

With this level of funding, the Center, will continue to:

- ✓ Partner with public and private entities – including state Title V programs for Children with Special Health Care Needs, pediatricians and primary care providers, families and parent organizations, professional societies and associations, Family-to-Family Health Information Centers, and state and community agencies such as Healthy Start, Head Start, and elementary schools – to expand the cadre of key stakeholders interested in promoting young children’s vision health and improving early identification of vision problems in young children.
- ✓ Develop and implement a statewide strategy to achieve universal screening of children by age four.
- ✓ Determine a mechanism for uniform collection and reporting of children’s vision care and eye health data.

With FY 2011 funding, the Center also will be able to:

- ✓ Broaden partnerships and expand coordination between the Center, the state agencies that administer the Title V Maternal and Child Health Block Grant, and other state public health entities to improve the early identification of vision problems in children.
- ✓ Support a consensus conference involving MCHB, CDC, the Agency for Healthcare Research and Quality, NEI, and the Office of Head Start to establish national standards for vision screening in young children.

⁹ “Our Vision for Children’s Vision: A National Call to Action for the Advancement of Children’s Vision and Eye Health, Prevent Blindness America,” Prevent Blindness America, 2008.

¹⁰ Otter WL, Scott WK, Holgado SI. Photoscreening for amblyogenic factors. *J Pediatr Ophthalmol Strabismus*. 1995; 32:289-295.

In addition, states need increased resources to sustain and expand the provision of critical health care services to millions of pregnant women, infants, and children, including those with vision and eye care needs. Beyond direct services, the Maternal and Child Health (MCH) Services Block Grant supports vital public health services and systems that promote optimal health and help prevent disease. Therefore, Prevent Blindness America supports appropriating \$730 million in FY 2011 for the Title V MCH Services Block Grant.

Advance and Expand Vision Research Opportunities

Prevent Blindness America calls upon the Subcommittee to increase its support for the NEI to bolster its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country. In 2009, Congress commended the NEI's leadership in basic and translational research through H. Res. 366 and S. Res. 209, which recognized NEI's 40 years as the National Institutes of Health Institute that leads the nation's commitment to save and restore vision. The resolutions also designated 2010-2020 as the *Decade of Vision* in recognition of the increasing health and economic burden of eye disease, mainly as a result of an aging population.

The NEI will be able to continue to grow its efforts to:

- ✓ Expand capacity for research, as demonstrated by the significant number of high-quality grant applications submitted in response to ARRA opportunities.
- ✓ Address unmet need, especially for programs of special promise that could reap substantial downstream benefits, as identified by new NIH Director Dr. Francis Collins.
- ✓ Fund research to reduce healthcare costs, increase productivity, and ensure the continued global competitiveness of the United States.

By increasing funding for the NEI at the NIH, essential efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention, treatment efforts and health information dissemination will be bolstered.

Conclusion

On behalf of Prevent Blindness America, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding FY 2011 funding for the CDC's Vision Health Initiative, the Maternal and Child Health Bureau's National Universal Vision Screening for Young Children Coordinating Center and Title V MCH Block Grants and the NEI. Please know that Prevent Blindness America stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to – and consideration of – our requests.

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Submitted by:
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The Prostatitis Foundation.
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To the Appropriations Subcommittee:

Prostatitis is a common disease among men. Almost all men get prostatitis in one form or another. Prostatitis has not received the discussion it deserves because many men are reluctant to discuss such matters even with their wives let alone friends and co-workers. Prostatitis is more common than prostate cancer but prostate cancer patients are less apt to assume a stigma about their disease than are prostatitis patients. Symptoms can be a combination of things such as waking at night to urinate, dribbling after urination, painful prostate and urinary frequency, inability to empty the bladder, sexual dysfunction, and infertility. Chronic prostatitis has subdued the intimacy inherent in many marriages and is responsible for much of the boom in the use of Viagra and Cialis.

There is no agreement among prostatitis researchers on the cause and cure for chronic prostatitis after eleven years of research and over 20 million dollars spent on clinical trials and data gathering. While researchers conclude that many common treatments might be effective to some small degree for chronic prostatitis a certain cure has not been discovered. Most researchers do agree that surgery is a poor idea for anything other than the disabled patient in severe extended pain. Many men still go from doctor to doctor searching for a treatment protocol that will help them. The word cure is seldom used as a cure has proven to be evasive in most cases.

The NIH phased out part of the previous research group and has a new group of researchers that includes other specialties besides urology, such as neurologists, pathologists, microbiologists, pain management specialists, and epidemiologists. As the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network they are coming together in Baltimore during March to reorganize a group to start over at a very basic level to see what can be determined appropriate for new research, for pelvic pain, for chronic prostatitis, interstitial cystitis, and irritable bowel syndrome; all covered by the umbrella term Pelvic Pain Syndrome. It is urgent that this research remains funded at a high level until a cause and cure can be determined.

Prostatitis will not be easily cured without better understanding than it has had and the discussion it deserves. Prostatitis has been as ubiquitous as the common cold far back into history. Famous men such as Napoleon and President John F. Kennedy suffered from prostatitis.

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The Prostatitis Foundation requests funding and enthusiastic support for the Mapp Network by the Appropriations Committee and the National Institute of Health until prostatitis is conquered for all men.

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TESTIMONY OF

MR. RINO ALDRIGHETTI
PRESIDENT
PULMONARY HYPERTENSION ASSOCIATION

ON BEHALF OF THE
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REGARDING

FISCAL YEAR 2011 APPROPRIATIONS FOR CDC, NIH AND HRSA

SUBMITTED TO THE
HOUSE LABOR-HHS-EDUCATION APPROPRIATIONS SUBCOMMITTEE

APRIL 16, 2010

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association (PHA).

I would like to extend my sincere thanks to the Subcommittee for your past support of pulmonary hypertension (PH) programs at the National Institutes of Health, Centers for Disease Control and Prevention, and Health Resources and Services Administration. These initiatives have opened many new avenues of promising research, helped educate hundreds of physicians in how to properly diagnose PH, and raised awareness about the importance of organ donation and transplantation within the PH community.

I particularly want to thank the subcommittee for the unprecedented support you provided to the NIH as part of the American Recovery and Reinvestment Act. PH research has benefitted substantially from that investment with more than 17 PH-specific projects receiving ARRA funding.

I am honored today to represent the hundreds of thousands of Americans who are fighting a courageous battle against a devastating disease. Pulmonary hypertension is a serious and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions such as: collagen vascular diseases (i.e., scleroderma and lupus), blood clots, HIV, sickle cell, or liver disease. PH impacts patients of all races, genders, and ages. Preliminary data from the REVEAL Registry suggests that

the ratio of women to men who develop PH is 4:1. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness, and fainting. Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, making it impossible to receive a necessary heart or lung transplant.

PH is chronic and incurable with a poor survival rate. Fortunately, new treatments are providing a significantly improved quality of life for patients with some managing the disorder for 20 years or longer.

Nineteen years ago, when three PH patients found each other, with the help of the National Organization for Rare Diseases, and founded the Pulmonary Hypertension Association, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was unacceptable, and formally established PHA, which is headquartered in Silver Spring, Maryland.

I am pleased to report that we are making good progress in our fight against this deadly disease. Six new therapies for the treatment of PH have been approved by the FDA in the past 10 years.

Today, PHA includes:

- Over 11,000 patients, family members, and medical professionals as members and an additional 49,000 supporters and friends.
- A network of over 200 patient support groups.
- An active and growing patient-to-patient telephone helpline.
- Three research programs that, through partnerships with the National Heart, Lung and Blood Institute, American Heart Association and the American Thoracic Society, have leveraged our donors' funds to commit more than \$7.5 million toward PH research as of December, 2009.
- Numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension – published quarterly and distributed to all cardiologists, pulmonologists, and rheumatologists in the U.S.
- A state-of-the-art website(www.phassociation.org) dedicated to providing educational and support resources to patients, caregivers, and the public.
- A new medical education website (www.phaonlineuniv.org), supported in part by the CDC, providing accredited medical education and resources to the medical community

THE PULMONARY HYPERTENSION COMMUNITY

Mr. Chairman, I am privileged to serve as the President of the Pulmonary Hypertension Association and to interact daily with the patients and family members who are seeking to live their lives to the fullest in the face of this deadly, incurable disease.

Carl Hicks is a former Army Ranger and a retired Colonel who led the first battalion into Iraq during the first Iraq war. Every member of his family was touched by pulmonary hypertension after the diagnosis of his daughter Meghan in 1994. I share their story here, in Carl's own words:

We're sorry Colonel Hides, your daughter Meaghan has contracted primary pulmonary hypertension. She likely has less than a year to live and there is nothing we can do for her.

“Those words were spoken in the spring of 1994 at Walter Reed Army Medical Center. They marked the start down the trail of tears for a young military family that, only hours before, had been in Germany. My family's journey down this trail hasn't ended yet, even though Meaghan's fight came to an end with her death on January 30th, 2009. She was 27.

Pulmonary hypertension (PH) struck our family, as it so often does, without warning. One day, we had a beautiful, healthy, energetic twelve-year old gymnast, the next, a child with a death sentence being robbed of every breath by this heinous disease. The toll of this fight was far-reaching. Over the years, every decision of any consequence in the family was considered first with regards to its impact on Meaghan and her *struggle for breath*.

The investment made by our country in my career was lost, as I left the service to stay nearer my family. The costs for Meaghan's medical care, spread over the nearly fourteen years of our fight, ran well into the seven figures. Meghan even underwent a heart and dual-lung transplant. These challenges, though, were *nothing* compared to the psychological toll of losing Meaghan who had fought so hard for something we all take for granted, a breath of air.”

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. As Meaghan's story illustrates, however, courageous patients of every age lose their battle with PH each day. There is still a long way to go on the road to a cure and biomedical research holds the promise of a better tomorrow.

Thanks to congressional action, and to advances in medical research largely supported by the NHLBI and other government agencies, PH patients have an increased chance of living with their pulmonary hypertension for many years. However, additional support is needed for research and related activities to continue to develop treatments that will extend the life expectancy of PH patients beyond the NIH estimate of 2.8 years after diagnosis.

FY 2011 APPROPRIATIONS RECOMMENDATIONS

A) NATIONAL HEART, LUNG AND BLOOD INSTITUTE

In 2008, World Health Organization's Fourth World Symposium on Pulmonary Hypertension brought together PH experts from around the world. According to these leading researchers, we are on the verge of significant breakthroughs in our understanding of PH and the development of new and advanced treatments. Fifteen years ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease. Thanks to advancements made through the public and private sector, patients today are living longer and better lives with a choice of seven FDA approved therapies. Recognizing that we have made tremendous progress, we are also mindful that we are a long way from where we want to be in 1) the management of PH as a treatable chronic disease, and 2) a cure.

We are grateful to the National Heart, Lung and Blood Institute for their leadership in advancing research on PH. Our Association is proud to jointly sponsor investigator training grants (K awards) with NHLBI aimed at supporting the next generation of pulmonary hypertension researchers.

Moreover, we were very pleased that NHLBI recently convened some of the community's leading scientists for a Working Group on Pulmonary Hypertension. This panel is charged with developing recommendations that will guide PH research in the coming years. An overview of the Working Group's plan will be published in the American Journal of Respiratory and Critical Care Medicine this year and we encourage the subcommittee to support its implementation by NHLBI.

Mr. Chairman, expanding clinical research remains a top priority for patients, caregivers, and PH investigators. We are particularly interested in establishing a pulmonary hypertension research network. Such a network would link leading researchers around the United States, providing them with access to a wider pool of shared patient data. In addition, the network would provide researchers with the opportunities to collaborate on studies and to strengthen the interconnections between basic and clinical science in the field of pulmonary hypertension research. Such a network is in the tradition of the NHLBI, which, to its credit and to the benefit of the American public, has supported numerous similar networks including the Acute Respiratory Distress Syndrome Network and the Idiopathic Pulmonary Fibrosis Clinical Research Network. We encourage the NHLBI to move forward with the establishment of a PH network in FY11.

For FY2011, PHA joins with other voluntary patient and medical organizations in recommending an appropriation of \$35 billion for the National Institutes of Health. This level of funding will ensure continued expansion of research on rare diseases like pulmonary hypertension and build upon the significant investment made in the NIH as part of the American Recovery and Reinvestment Act.

B) CENTERS FOR DISEASE CONTROL AND PREVENTION

Mr. Chairman, we are grateful to you and the subcommittee for providing funding in FY10 for the continuation of PHA's Pulmonary Hypertension Awareness Campaign. We know for a fact that Americans are dying due to a lack of awareness of PH, and a lack of understanding about the many new treatment options. This unfortunate reality is particularly true among minority and underserved populations. More needs to be done to educate both the general public and healthcare providers if we are to save lives.

To that end, PHA has utilized the funding provided through the CDC to; 1) launch a successful media outreach campaign focusing on both print and online outlets; 2) expand our support programs for previously underserved patient populations; and; 3) establish *PHA Online University*, an interactive curriculum-based website for medical professionals that targets pulmonary hypertension experts, primary care physicians, specialists in pulmonology/ cardiology/ rheumatology, and allied health professionals. The site is continually updated with information on early diagnosis and appropriate treatment of pulmonary hypertension. It serves as a center point for discussion among PH-treating medical professionals and offers Continuing Medical Education and CEU credits through a series of online classes.

We encourage the subcommittee to continue its support for PH education and awareness activities in FY11. These initiatives are making a real difference in the fight against this devastating disease.

C) "GIFT OF LIFE" DONATION INITIATIVE AT HRSA

PHA applauds the success of the Health Resources and Services Administration's "Gift of Life" Donation Initiative. This important program is working to increase organ donation rates across the country. Unfortunately, the only "treatment" option available to many late-stage PH patients is a lung, or heart and lung, transplantation. This grim reality is why PHA established "Bonnie's Gift Project."

"Bonnie's Gift" was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness. PHA will use "Bonnie's Gift" as a way to disseminate information about PH, transplantation, and the importance of organ donation, as well as organ donation cards, to our community.

PHA has had a very successful partnership with HRSA's "Gift of Life" Donation Program in recent years. Collectively, we have worked to increase organ donation rates and raise awareness about the need for PH patients to "early list" on transplantation waiting lists. For FY 2011, PHA recommends an appropriation of \$30 million for this important program.

D) SOCIAL SECURITY DISABILITY

Finally Mr. Chairman, PHA would like to thank the subcommittee for its commitment to address the longstanding backlog of disability claims at the Social Security Administration. We greatly appreciate this investment as a growing number of our patients are applying for disability coverage. On a related note, the SSA recently convened a panel of leading cardiologists to review and revise the disability criteria for cardiovascular diseases. This Institute of Medicine committee has taken a particular interest in PH and is working with our medical experts to update the disability criteria for our patient population. We encourage Congress to support this process moving forward.

Once again, thank you for the opportunity to present our views. If you have any questions, or require additional information, please do not hesitate to contact me.

**RAILROAD RETIREMENT BOARD
FISCAL YEAR 2011 BUDGET REQUEST**

Statement for the Record, April 15, 2010

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH
AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**

Michael S. Schwartz, Chairman of the Board

V. M. Speakman, Jr., Labor Member of the Board

Jerome F. Keever, Management Member of the Board

Mr. Chairman and Members of the Committee:

We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2011 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. During the past year, the RRB has also administered special economic recovery payments and extended unemployment benefits under the American Recovery and Reinvestment Act of 2009, and more recently, extended unemployment benefits under the Worker, Homeownership, and Business Assistance Act of 2009.

During fiscal year 2009, the RRB paid \$10.5 billion, net of recoveries, in retirement/survivor benefits and vested dual benefits to about 589,000 beneficiaries. We also paid \$154.1 million in net unemployment/sickness insurance benefits under the Railroad Unemployment Insurance Act to more than 40,000 claimants. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to \$1.3 billion to about 115,000 beneficiaries, and we paid about \$129.5 million in Economic Recovery Payments and \$10.3 million in temporary extended unemployment benefits under the American Recovery and Reinvestment Act to about 518,700 beneficiaries and 3,100 claimants, respectively.

PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The President's proposed budget would provide \$110,573,000 for agency operations, which would enable us to maintain a staffing level of 891 full-time equivalent staff years (FTEs) in 2011. The proposed budget would also provide \$1,500,000 for information technology (IT) investments. This includes \$850,000 for costs related to an upgrade of the agency's mainframe computer. The remaining IT funds would be used for information

security and privacy, E-Government initiatives, systems modernization, network operations, and some infrastructure replacement.

AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. Nearly 70 percent of our employees have 20 or more years of service at the agency, and about 40 percent of the current workforce will be eligible for retirement by fiscal year 2012.

To prepare for expected staff turnover in the near future, we are focusing on activities related to workforce planning and development. During the past year, the agency drafted a formal human capital plan that adheres to guidance issued by the Office of Personnel Management. The plan identifies demographic features of the agency's workforce and the skills needed to fulfill our mission. The plan also establishes a framework of actions over the next few years to recruit, retain and develop talented employees. We have also drafted a succession plan that specifies staffing needed to meet organizational goals, identifies competency gaps and develops strategies to address overall human capital needs.

In connection with these workforce planning efforts, our budget request for fiscal year 2011 includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b) (9) of the Railroad Retirement Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby enabling the RRB to use various hiring authorities offered by the Office of Personnel Management.

INFORMATION TECHNOLOGY IMPROVEMENTS

In recent years, we have undertaken a series of strategic measures to improve computer processes and better position the RRB for the future. First, the agency moved to a relational database environment, and then optimized the data that reside in the legacy databases. In fiscal year 2009, we began a multi-year initiative to modernize our application systems, starting with Medicare processing systems. This effort will enable the RRB to maintain the capability of our business operations in the event of expected staff turnover, and to upgrade agency systems by building on the improvements that we have already completed. Much of the work related to this initiative will be completed by in-house staff. Our budget request for fiscal year 2011 includes \$150,000 for minimal contractual services related to the initiative.

In order to keep pace with these planned improvements, it will be necessary to increase the capacity of our mainframe computer. In fiscal year 2008, a new mainframe computer was installed with scalability to provide for additional processing capacity as demand increases. Since then, demand for additional processing capacity has increased an average of 18 percent each year with the completion of various automation initiatives. Our

fiscal year 2011 budget request includes \$850,000 to upgrade the RRB's mainframe computer software in order to meet the rising demand for capacity.

Our proposed budget also includes an additional \$500,000 for other information technology investments. This funding will provide for essential equipment and services needed to maintain our network operations and infrastructure in fiscal year 2011, and to continue with other initiatives, such as E-Government and information security and privacy.

The President's proposed budget includes \$57 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, \$1,140,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits."

In addition to the requests noted above, the President's proposed budget includes \$150,000 for interest related to uncashed railroad retirement checks.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts – The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The market value of Trust-managed assets on September 30, 2009, was approximately \$23.3 billion, a decrease of \$2 billion from the previous year. Since its inception, the Trust has transferred approximately \$8.9 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

In June 2009, we released the 24th Actuarial Valuation, including the annual report on the railroad retirement system required by Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The actuarial valuation indicates that cash flow problems occur only under the most pessimistic assumption. Even under that assumption, the cash flow problems do not occur until the year 2031. The long-term stability of the system, however, is not assured. Under the current financing structure, actual levels of railroad employment and investment performance over the coming years will determine whether additional corrective action is necessary.

Railroad Unemployment Insurance Account – The equity balance of the Railroad Unemployment Insurance (RUI) Account at the end of fiscal year 2009 was \$27.8 million, a decrease of \$72.1 million from the previous year. The RRB's latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2009. The report indicated that even as maximum daily benefit rates rise 43 percent (from \$61 to \$87) from 2008 to 2019, experience-based contribution rates are expected to keep the unemployment insurance system solvent, except for small, short-term cash-flow problems in

2010 and 2011 under the moderate and pessimistic assumptions. Projections show a quick repayment of loans even under the most pessimistic assumption.

Unemployment levels are the single most significant factor affecting the financial status of the railroad unemployment insurance system. However, the system's experience-rating provisions, which adjust contribution rates for changing benefit levels, and its surcharge trigger for maintaining a minimum balance, help to ensure financial stability in the event of adverse economic conditions. No financing changes were recommended at this time by the report.

Due to the increased level of unemployment insurance payments during fiscal year 2009 and anticipated for fiscal year 2010, loans from the Railroad Retirement (RR) Account to the RUI Account became necessary beginning in December 2009. Transfers from the RR Account to the RUI Account through February 2010 amounted to \$24.5 million. Current projections indicate that additional loans from the RR Account to the RUI Account during fiscal year 2010 could amount to approximately \$43.5 million, for a total of \$68 million during the fiscal year.

In conclusion, we want to stress the RRB's continuing commitment to improving our operations and providing quality service to our beneficiaries. Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

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**MARTIN J. DICKMAN, INSPECTOR GENERAL
RAILROAD RETIREMENT BOARD
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**BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES
OF THE COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES**

**TESTIMONY OF THE INSPECTOR GENERAL FOR THE
RAILROAD RETIREMENT BOARD**

April 9, 2010

Mr. Chairman and Members of the Subcommittee:

My name is Martin J. Dickman and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the Subcommittee for your continued support of the Office of Inspector General.

BUDGET REQUEST AND BACKGROUND INFORMATION

I wish to describe our Fiscal Year (FY) 2011 appropriations request and our planned activities. The Office of Inspector General (OIG) respectfully requests funding in the amount of \$8,936,000 to ensure the continuation of its independent oversight of the Railroad Retirement Board (RRB).

The RRB's central mission is to pay accurate and timely benefits. During FY 2009, the RRB paid approximately \$10.5 billion in retirement and survivor benefits to 589,000 beneficiaries. RRB also paid roughly \$154.1 million in net unemployment and sickness insurance benefits to almost 24,000 unemployment insurance beneficiaries and 18,000 sickness insurance beneficiaries.

The RRB contracts with a separate Medicare Part B carrier, Palmetto GBA, to process the Medicare Part B claims of qualified railroad retirement beneficiaries. As of September 30, 2009, there were about 468,000 such beneficiaries enrolled in the Medicare Part B program through the RRB. During FY 2009, Palmetto, GBA paid over \$900 million in benefits.

During FY 2011, the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

OPERATIONAL COMPONENTS

The OIG has three operational components: the immediate Office of the Inspector General, the Office of Audit (OA), and the Office of Investigations (OI). The OIG conducts operations from several locations: the RRB's headquarters in Chicago, Illinois; an investigative field office in Philadelphia, Pennsylvania; and three domicile investigative offices located in Arlington, Virginia; Houston, Texas; and San Diego, California. These domicile offices provide more effective and efficient coordination with other Inspector General offices and traditional law enforcement agencies with which the OIG works joint investigations.

OFFICE OF AUDIT

It is OA's mission to:

- promote economy, efficiency, and effectiveness in the administration of RRB programs and
- detect and prevent fraud and abuse in such programs.

To accomplish its mission, OA conducts financial, performance, and compliance audits and evaluations of RRB programs. In addition, OA develops the OIG's response to audit-related requirements and requests for information.

During FY 2011, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified four broad areas of potential audit coverage:

- Financial Accountability;
- Railroad Retirement Act & Railroad Unemployment Insurance Act Benefit Program Operations;
- Railroad Medicare Program Operations, including activities of Palmetto, GBA; and
- Security, Privacy, and Information Management.

During FY 2011, OA must accomplish the following mandated activities with its own staff:

- Audit of the RRB's financial statements pursuant to the requirements of the Accountability of Tax Dollars Act of 2002 and
- Evaluation of information security pursuant to the Federal Information Security Management Act (FISMA).

During FY 2011, OA will complete the audit of the RRB's FY 2010 financial statements and begin its audit of the agency's FY 2011 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance" which became basic financial information effective for FY 2006. In FY 2011, the cost of this contract is expected to increase significantly over the current contract amount.

In addition to performing the annual evaluation of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA considers staff availability, current trends in management, Congressional and Presidential concerns.

OFFICE OF INVESTIGATIONS

OI focuses its efforts on identifying, investigating, and presenting benefit fraud cases for prosecution. OI conducts investigations, throughout the United States, relating to the fraudulent receipt of RRB disability, unemployment, sickness, retirement/survivor and Railroad Medicare benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also investigates allegations regarding agency employee misconduct and threats against RRB employees. Investigative efforts can result in criminal convictions, administrative sanctions, civil penalties and/or the recovery of program benefit funds.

OI's investigative results for FY 2009 are:

| Civil Judgments | Indictments/ Informations | Convictions | Recoveries/ Collections |
|------------------------|----------------------------------|--------------------|--------------------------------|
| 29 | 78 | 48 | \$7,056,086 |

OI initiates cases based on information from a variety of sources. The agency conducts computer matching of employment and earnings information reported to state governments and the Social Security Administration with RRB benefits paid data. Referrals are made to OI if a match is found. OI also receives allegations of fraud through the OIG Hotline, contacts with state, local and Federal agencies, and information developed through audits conducted by the OIG's Office of Audit.

Presently, disability and Railroad Medicare fraud cases constitute more than 60% of OI's total caseload. These cases often involve complicated schemes and result in the recovery of substantial funds for the agency's trust funds. They also require considerable time and resources such as travel by special agents to conduct surveillance, numerous witness interviews, or more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and involve complicated financial analysis.

During FY 2011, OI anticipates an ongoing caseload of more than 400 investigations. OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

CONCLUSION

In FY 2011, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies.

The OIG sincerely appreciates its cooperative relationship with the agency and the ongoing assistance extended to its staff during the performance of their audits and investigations. Thank you for your consideration.



**Written Testimony Submitted by Kathleen Clanon, MD
Co-Chair, Ryan White Medical Providers Coalition**

kclanon@jba-cht.com/510-612-5548

to the U.S. House Appropriations Subcommittee on

Labor, Health and Human Services, Education and Related Agencies

**Regarding Part C of the Ryan White Program at the HIV/AIDS Bureau of the Health
Resources and Services Administration in the Department of Health and Human Services**

April 12, 2010

Introduction

I am Dr. Kathleen Clanon, an HIV physician and Medical Director of the HIV ACCESS program in Oakland, California. I am submitting written testimony on behalf of the Ryan White Medical Providers Coalition.

Thank you for the opportunity to discuss the important HIV/AIDS care conducted at Ryan White Part C funded programs nationwide. Specifically, the Ryan White Medical Provider Coalition, the HIV Medicine Association, the CAEAR Coalition, and the American Academy of HIV Medicine estimate that approximately \$407 million is needed to provide the standard of care for all Part C program patients. (This estimate is based on the current cost of care and the number of patients that Part C clinics serve.) While these are exceptionally challenging economic times, we request **\$338 million for Ryan White Part C programs in FY 11. This \$131 million funding increase** would help meet the goal of providing the standard of care to all patients who need it.

The Ryan White Medical Providers Coalition was formed in 2006 to be a voice for medical providers across the nation delivering quality care to their patients through Part C of the Ryan White program. We represent every kind of program, from small and rural to large urban sites in every region in the country. We speak for those who often cannot speak for themselves and we advocate for a full range of primary care services for these patients. Sufficient funding for Part C is essential to providing appropriate care for individuals living with HIV/AIDS.

Part C of the Ryan White Program funds comprehensive HIV care and treatment, services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. The Centers for Disease Control and Prevention estimate that there are more than 1.1 million persons living with HIV/AIDS, and in 2008 *approximately 240,000, or almost 1 in 4*, of these individuals received services from Part C medical providers -- a dramatic *30% increase in patients in less than 10 years*.

The recent passage of health care reform is a great achievement, but many of the legislation's provisions and programs will not take effect for several years. In the meantime, Part C clinics need additional resources today to continue delivering lifesaving and cost-effective care to the growing number of people living with HIV.

The Cost of Care Is Reasonable; The Reimbursement for Care Isn't

On average it costs *\$3,501 per person per year* to provide the comprehensive outpatient care and treatment available at Part C funded programs, including lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. Part C funding covers only a small percentage of the total cost of this comprehensive care, with some programs receiving *\$450 (12 percent of the total cost) or less per patient per year to cover the cost of care.*

Part C Programs Save Both Lives and Money

Investing in Part C services improves lives and saves money. In the U.S., nearly 50% of persons living with HIV/AIDS who are aware of their status are not in regular care. Early and reliable access to HIV care and treatment both helps patients with HIV live relatively *healthy and productive lives* and is *more cost effective*. One study from the Part C Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required *2.6 times more health care dollars* than those receiving earlier treatment meeting federal HIV treatment guidelines.

Patient Loads Are Increasing at an Unsustainable Rate

Patient loads have been increasing at Part C clinics nationwide, despite the fact that there has not been significant new federal funding, and in many cases, state and/or local funding has been cut. A steady increase in patients has occurred on account of higher diagnosis rates and declining insurance coverage resulting in part from the economic downturn. The CDC reports that the number of *HIV/AIDS cases increased by 15 percent from 2004 to 2007 in 34 states.*¹

For example, A clinic in Henderson, N.C., has seen its *patient load increase almost nine fold* from 35 patients in 2000 to nearly 300 today, yet the clinic is receiving *less funding now than 10 years ago*. This clinic is the only facility of its kind for people with HIV within 45 miles and it is struggling to deliver the complex care these patients need. At another clinic in Greensboro, N.C., the number of patients more than doubled from 321 patients in 2002 to more than 800 in 2009. The clinic continues to deliver care in the same space with the same staffing as in 2002 despite the *250 percent increase in patients*. Meeting this growing demand requires the maximum effort of existing staff, and position vacancies prevented enrollment of new patients for several months during 2009. In Sonoma County, California, funding has become so scarce that *the Part C clinic there is closing its doors*, forced to patch together new medical homes in other locations for 350 patients.

Our patients struggle in times of plenty, and during this economic downturn they have relied on Part C programs more than ever. While these programs have been under-funded for years, state and local economic pressures are creating a crisis in our communities. Clinics are *discontinuing*

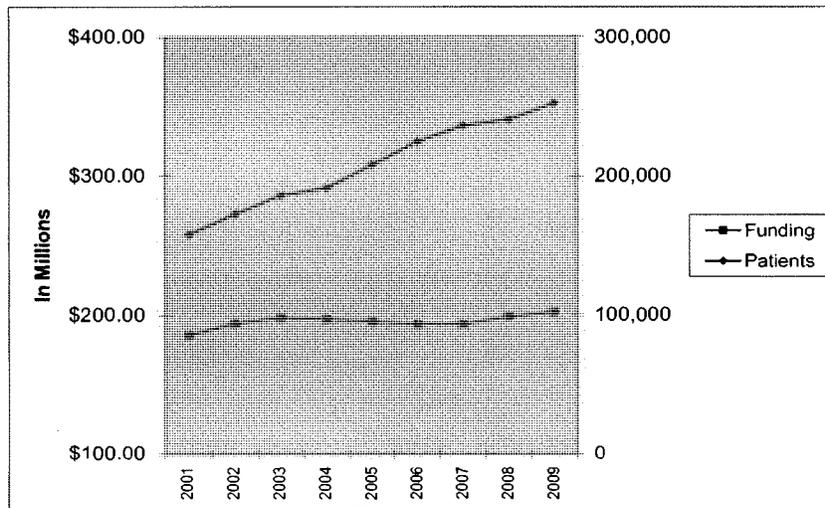
¹ Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2007. Vol. 19. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2009:5. www.cdc.gov/hiv/topics/surveillance/resources/reports/.

primary care and other critical medical services, such as laboratory monitoring; suffering eviction from their clinic locations; operating only 4 days per week; and laying off staff just to get by. Years of nearly flat funding combined with large increases in the patient population and the recent economic crisis are negatively impacting the ability of Part C providers to serve their patients.

The following graph demonstrates the growing disparity between funding for Part C and the increasing patient population. I refer to this gap between funding and patients as the “Triangle of Misery” because it represents both the thousands of patients who deserve more than we can offer and the Part C programs nationwide that are struggling to serve them with shrinking resources.

THE TRIANGLE OF MISERY

2001 to 2009: Part C Patients Increased by 59%, While Funding Only Increased by 8.6%



NOTE: 2009 data is estimated and assumes a 4.9 percent increase based on the average increase over the past three years.

Conclusion

These are challenging economic times, and we recognize the severe fiscal constraints Congress faces in allocating limited federal dollars. However, Congress itself has recognized the need to substantially increase Part C funds in its recent passage of the reauthorization of the Ryan White Program in September 2009. *In this law, Congress recommended funding Ryan White Part C Programs at \$259 million in FY 11, a \$52 million increase over the FY 10 funding level.*

The significant financial and patient pressures that we face in our clinics at home propel us to request a substantial federal investment of **\$338 million in FY 11 for Ryan White Part C programs** to support medical providers nationwide in delivering appropriate and effective HIV/AIDS care to their patients. Thank you for your time and consideration of our request, and if you have any questions, please do not hesitate to contact the Ryan White Medical Providers Coalition Convener, Jenny Collier, at jennycollierjd@yahoo.com or 202-295-7188.

Bill Daniels
Safety Leader, Americas
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Dear Members of the House Appropriations Committee:

I would like to take this opportunity to speak up against the idea of a fee-based Voluntary Protection Programs (VPP). As someone who's been involved with the VPP program for more than 12 years at three different sites, and currently the VPP coordinator at eight manufacturing sites, I believe that this will be detrimental to the integrity of the program and the culture of proactive safety and health beyond compliance that it currently instills. Funding VPP through a user-fee system for certification would take away from the independent verification of our safety and health management system because it would lead to a direct relationship between number of VPP sites and fees paid to the government. I feel strongly for the following reasons this should not be done:

- Industry directly funding the government to perform part of its required function under the OSH Act.
- Creating the perception that employers are "buying" the VPP flag.
- Creating a situation where employers can be perceived as purchasing "an exemption from routine OSHA inspections."
- Fees for VPP deterring small businesses from participating.
- Charging sites for participation in VPP despite of what VPP sites voluntarily give in the form of mentoring, outreach, assist visits, funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national conferences.
- Paying a fee reduces VPP to a government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride.

Unlike many fee-based certification programs, VPP is a comprehensive workplace safety and health management system that is built on cooperation among workers, employers and government. If the DOL backs away from the partnership, it diminishes the program instead of strengthening OSHA's partnership with corporate America in an effort to push beyond outdated standards.

While I continue to support firm and fair enforcement as a necessary tool to reach worksites that are not voluntarily improving their safety and health programs, I firmly believe that there is clear evidence that 40 years of enforcement has failed in producing the necessary culture shift that is required to achieve measurable and sustainable improvements in the protection of the American workforce and to keep American businesses competitive in a global marketplace.

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I ask you to speak out against the idea of a fee-based Voluntary Protection Programs and to ensure the continued success of OSHA's VPP as a cooperative program by reinstating direct and continued funding in the DOL budget. Highly successful cooperative programs like VPP should be funded and expanded if OSHA is to assist American businesses in achieving the necessary cultural change required to maintain and protect American workers, which is a proven method that supports OSHA's mission. I ask that you provide full funding in the DOL budget for VPP and include specific Appropriations language to restore and direct the Agency to fund, resource load and conduct VPP assistance, application evaluations, onsite re-approvals and new onsite evaluations to the levels equal to or greater than those achieved in 2005.

Sincerely,

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**STATEMENT OF
BRIAN R. ADAMS
EXECUTIVE DIRECTOR
SOUTHERN CALIFORNIA CHAPTER OF THE SCLERODERMA FOUNDATION
ON BEHALF OF
CYNTHIA CERVANTES
(310) 477-8225
SCLERODERMASOCAL@HOTMAIL.COM**

**ON BEHALF OF THE
THE SCLERODERMA FOUNDATION
300 ROSEWOOD DRIVE SUITE 105
DANVERS, MA 01923**

ON

**FISCAL YEAR 2011 APPROPRIATIONS FOR THE
DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**SUBMITTED TO THE
HOUSE APPROPRIATIONS COMMITTEE; SUBCOMMITTEE ON LABOR, HEALTH
AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES**

APRIL 16, 2010

**Statement of Cynthia Cervantes
Huntington Park, California
Scleroderma Foundation**

Mr. Chairman, I am Cynthia Cervantes, I am 12 and in the ninth grade. I live in Southern California and in October 2006 I was diagnosed with scleroderma. Scleroderma means "hard skin" which is literally what scleroderma does and, in my case, also causes my internal organs to stiffen and contract. This is called diffuse scleroderma. It is a relatively rare disorder effecting only about 300,000 Americans.

About 2 years ago I began to experience sudden episodes of weakness, my body would ache and my vision was worsening, some days it was so bad I could barely get myself out of bed. I was taken to see a doctor after my feet became so swollen that calcium began to ooze out. It took the doctors (period of time) to figure out exactly what was wrong with me, because of how rare scleroderma is.

There is no known cause for scleroderma, which affects three times as many women as men. Generally, women are diagnosed between the ages of 25 and 45, but some kids, like me, are affected earlier in life. There is no cure for scleroderma, but it is often treated with skin softening agents, anti-inflammatory medication, and exposure to heat. Sometimes a feeding tube must be used with a scleroderma patient because their internal organs contract to a point where they have extreme difficulty digesting food.

The Scleroderma Foundation has been very helpful to me and my family. They have provided us with materials to educate my teachers and others about my disease. Also, the support groups the foundation helps organize are very helpful because they help show me that I can live a normal, healthy life, and how to approach those who are curious about why I wear gloves, even in hot weather. It really means a lot to me to be able to interact with other people in the same situation as me because it helps me feel less alone.

Mr. Chairman, because the causes of scleroderma are currently unknown and the disease is so rare, and we have a great deal to learn about it in order to be able to effectively treat it. I would like to ask you to please significantly increase funding for the National Institute of Health so treatments can be found for other people like me who suffer from scleroderma. It would also be helpful to start a program at the Centers for Disease Control and Prevention to educate the public and physicians about scleroderma.

OVERVIEW OF THE SCLERODERMA FOUNDATION AND SCLERODERMA

SCLERODERMA FOUNDATION

The Scleroderma Foundation is a nonprofit organization based in Danvers, MA with a three-fold mission of support, education, and research. The Foundation has 21 chapters nationwide and over 175 support groups.

The Scleroderma Foundation was established on January 1, 1998 through a merger between two organizations, one on the west coast and one on the east coast, which can trace their beginnings

back to the early 1970s. The Foundation's mission is to provide support for people living with scleroderma and their families through programs such as peer counseling, doctor referrals, and educational information, along with a toll-free telephone helpline for patients and a quarterly magazine, *The Scleroderma Voice*.

The Foundation also provides education about the disease to patients, families, the medical community, and the general public through a variety of awareness programs at both the local and national levels. Over \$1 million in peer-reviewed research grants are awarded annually to institutes and universities to stimulate progress in the search for a cause and cure for scleroderma. Building awareness of the disease to patients, families, the medical community and the general public to not only generate more funding for medical research, but foster a greater understanding of the complications faced by people living with the disease is a further major focus.

Among the many programs arranged by the Foundation is the Annual Patient Education Conference held each summer. The conference brings together an average of 500 attendees and experts for a wide range of workshops on such topics as the latest research initiatives, coping and disease management skills, caregiver support, and exercise programs.

WHO GETS SCLERODERMA?

There are many clues that define susceptibility to develop scleroderma. A genetic basis for the disease has been suggested by the fact that it is more common among patients whose family members have other autoimmune diseases (such as lupus). In rare cases, scleroderma runs in families, although for the vast majority of patients there is no other family member affected. Some Native Americans and African Americans get worse scleroderma disease than Caucasians.

Women are more likely to get scleroderma. Environmental factors may trigger the disease in the susceptible host. Localized scleroderma is more common in children, whereas scleroderma is more common in adults. However, both can occur at any age.

There are an estimated 300,000 people in the United States who have scleroderma, about one third of whom have the systemic form of scleroderma. Diagnosis is difficult and there may be many misdiagnosed or undiagnosed cases as well.

Scleroderma can develop and is found in every age group from infants to the elderly, but its onset is most frequent between the ages of 25 to 55. There are many exceptions to the rules in scleroderma, perhaps more so than in other diseases. Each case is different.

CAUSES OF SCLERODERMA

The cause is unknown. However, we do understand a great deal about the biological processes involved. In localized scleroderma, the underlying problem is the overproduction of collagen (scar tissue) in the involved areas of skin. In systemic sclerosis, there are three processes at work: blood vessel abnormalities, fibrosis (which is overproduction of collagen) and immune system dysfunction, or autoimmunity.

RESEARCH

Research suggests that the susceptible host for scleroderma is someone with a genetic predisposition to injury from some external agent, such as a viral or bacterial infection or a substance in the diet or environment. In localized scleroderma, the resulting damage is confined to the skin. In systemic sclerosis, the process causes injury to blood vessels, or indirectly perturbs the blood vessels by activating the immune system.

Research continues to assemble the pieces of the scleroderma puzzle to identify the susceptibility genes, to find the external trigger and cellular proteins driving fibrosis, and to interrupt the networks that perpetuate the disease.

Unfortunately, support for scleroderma research at the National Institutes of Health over the past several years has been relatively flat funded at \$20 million in FY08, \$21 million in FY09, and an estimated \$22 million in FY10. This slow rate of increase is extremely frustrating to our patients who recognize biomedical research as their best hope for a better quality of life. It is also of great concern to our researchers who have promising ideas they would like to explore if resources were available.

TYPES OF SCLERODERMA

There are two main forms of scleroderma: systemic (systemic sclerosis, SSc) that usually affects the internal organs or internal systems of the body as well as the skin, and localized that affects a local area of skin either in patches (morphea) or in a line down an arm or leg (linear scleroderma), or as a line down the forehead (scleroderma en coup de sabre). It is very unusual for localized scleroderma to develop into the systemic form.

Systemic Sclerosis (SSc)

There are two major types of systemic sclerosis or SSc: limited cutaneous SSc and diffuse cutaneous SSc. In limited SSc, skin thickening only involves the hands and forearms, lower legs and feet. In diffuse cutaneous disease, the hands, forearms, the upper arms, thighs, or trunk are affected.

The face can be affected in both forms. The importance of making the distinction between limited and diffuse disease is that the extent of skin involvement tends to reflect the degree of internal organ involvement.

Several clinical features occur in both limited and diffuse cutaneous SSc. Raynaud's phenomenon occurs in both. Raynaud's phenomenon is a condition in which the fingers turn pale or blue upon cold exposure, and then become ruddy or red upon warming up. These episodes are caused by a spasm of the small blood vessels in the fingers. As time goes on, these small blood vessels become damaged to the point that they are totally blocked. This can lead to ulcerations of the fingertips.

People with the diffuse form of SSc are at risk of developing pulmonary fibrosis (scar tissue in the lungs that interferes with breathing, also called interstitial lung disease), kidney disease, and bowel disease.

The risk of extensive gut involvement, with slowing of the movement or motility of the stomach and bowel, is higher in those with diffuse rather than limited SSc. Symptoms include feeling bloated after eating, diarrhea or alternating diarrhea and constipation.

Calcinosis refers to the presence of calcium deposits in, or just under, the skin. This takes the form of firm nodules or lumps that tend to occur on the fingers or forearms, but can occur anywhere on the body. These calcium deposits can sometimes break out to the skin surface and drain whitish material (described as having the consistency of toothpaste).

Pulmonary Hypertension (PH) is high blood pressure in the blood vessels of the lungs. It is totally independent of the usual blood pressure that is taken in the arm. This tends to develop in patients with limited SSc after several years of disease. The most common symptom is shortness of breath on exertion. However, several tests need to be done to determine if PH is the real culprit. There are now many medications to treat PH.

Localized Scleroderma

Morphea

Morphea consists of patches of thickened skin that can vary from half an inch to six inches or more in diameter. The patches can be lighter or darker than the surrounding skin and thus tend to stand out. Morphea, as well as the other forms of localized scleroderma, does not affect internal organs.

Linear scleroderma

Linear scleroderma consists of a line of thickened skin down an arm or leg on one side. The fatty layer under the skin can be lost, so the affected limb is thinner than the other one. In growing children, the affected arm or leg can be shorter than the other.

Scleroderma en coup de sabre

Scleroderma en coup de sabre is a form of linear scleroderma in which the line of skin thickening occurs on the forehead or elsewhere on the face. In growing children, both linear scleroderma and en coup de sabre can result in distortion of the growing limb or lack of symmetry of both sides of the face.

FY11 APPROPRIATIONS RECOMMENDATIONS

- A increase in funding for the National Institutes of Health (NIH) to \$35 billion.
 - An increase for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) concurrent with the overall increase to NIH.
- Committee recommendation encouraging the Centers for Disease Control and Prevention to partner with the Scleroderma Foundation to promoting increased awareness of scleroderma among the general public and health care providers.

SIECUS

Sexuality Information and Education
Council of the United States

90 John Street, Suite 704, New York, NY 10038 | 212 819 9770 | 212 819 9776 | 1706 R Street NW, Washington, DC 20009 | 202 265 2405 | 202 462 2343 | siecus.org

Public Witness Testimony
Sexuality Information and Education Council of the United States (SIECUS)
Jen Heitel Yakush, Director of Public Policy, jyakush@siecus.org

Fiscal Year 2011 House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, and Education

Submitted for the Record
April 12, 2010

SIECUS, the Sexuality Information and Education Council of the United States, has served as a strong national voice for sexuality education, sexual health, and sexual rights for over 45 years. SIECUS affirms that sexuality is a fundamental part of being human, one that is worthy of dignity and respect. We advocate for the right of all people to accurate information, comprehensive education about sexuality, and sexual health services. SIECUS works to create a world that ensures social justice and sexual rights.

President's Teen Pregnancy Prevention Initiative at the Office of Adolescent Health

As an organization committed to the health and education of our nation's young people, we urge the committee to invest in programs that provide all of our nation's youth with comprehensive, medically accurate, and age-appropriate sex education that helps them reduce their risk of unintended pregnancy, HIV, and other sexually transmitted infections (STIs), as well as teach them about healthy relationships and communication and decision-making skills so they can make responsible decisions and lead safe and healthy lives.

For the first time in more than a decade, the nation's teen pregnancy rate rose 3% in 2006. During this time, teens were receiving less information about contraception in schools and their use of contraceptives was declining. Moreover, while making up only one-quarter of the sexually active population, young people aged 15–24 account for roughly half of the approximately 19 million new cases of sexually transmitted infections (STIs) each year. Those aged 13–24 account for one-sixth of new HIV infections, the largest share of any age group.

We are pleased that the President's Fiscal Year 2011 budget request once again included funding for more comprehensive and evidence-based approaches to sex education. However, by focusing the funding on teen pregnancy prevention, and not including the equally important health issues of STIs including HIV, the Administration has missed an opportunity to provide true, comprehensive sex education that promotes healthy behaviors and relationships for all young people, including lesbian, gay, bisexual, and transgender (LGBT) youth. We must strategically and systemically provide young people with all the information and services they need to make responsible decisions about their sexual health. Therefore, we request that the teen pregnancy

prevention initiative be broadened to address STIs, including HIV, in addition to the prevention of unintended teen pregnancy.

Most of the evidence-based programs that have been proven effective at reducing risk factors associated with unintended teenage pregnancy and STIs by delaying sexual activity and increasing contraceptive use emphasize abstinence as the safest choice and also discuss contraceptive use as a way to avoid pregnancy and STIs, including HIV. In light of the evidence and recognizing over half of young people have had sexual intercourse by the age of 18 and are at risk of both unintended pregnancy and STIs, we request that the committee direct the Office of Adolescent Health to prioritize funds to programs that are more comprehensive in scope insofar as they encourage abstinence but also encourage young people to always use condoms or other contraceptives when they are sexually active.

Leading public health and medical professional organizations—including the American Medical Association, the American Academy of Pediatrics, the Society of Adolescent Medicine, and the American Psychological Association—support a comprehensive approach to educating young people about sex. Focusing on more comprehensive approaches is both good policy and good politics. It is good policy because it is based on scientific considerations and takes into account the reality of teens' lives. In sharp contrast to abstinence-only-until-marriage programs, there is strong evidence that more comprehensive approaches do help young people both to withstand the pressures to have sex too soon and to have healthy, responsible, and mutually protective relationships when they do become sexually active. Importantly, the evidence is strong that sex education programs that promote abstinence as well as the use of condoms do not increase sexual behavior. Studies show that when teens are educated about condoms and have access to the method, levels of condom use at first intercourse increase while levels of sex stay the same.

Moreover, the CDC's Task Force on Community Preventive Services recently reviewed Comprehensive Risk Reduction programs and found sufficient evidence to recommend their use and support a conclusion that Comprehensive Risk Reduction interventions can have a beneficial effect on public health. The recommendation is based on sufficient evidence of effectiveness in: reducing a number of self-reported risk behaviors, including (1) engagement in any sexual activity, (2) frequency of sexual activity, (3) number of partners, and (4) frequency of unprotected sexual activity; (5) increasing the self-reported use of protection against pregnancy and STIs; and (6) reducing the incidence of self-reported or clinically-documented sexually transmitted infections.

In addition, the vast majority of parents want the federal government to fund programs that are medically accurate, age-appropriate, and educate youth about both abstinence and contraception. Nationwide polls show that eight-in-ten voters want young people to receive a comprehensive approach to sex education that includes teaching about both abstinence and contraception. Furthermore, according to the results of a 2005–2006 nationally representative survey of U.S. adults, published in the *Archives of Pediatrics and Adolescent Medicine*, there is far greater support for comprehensive sex education than for the abstinence-only approach, regardless of respondents' political leanings and frequency of attendance at religious services. Overall, 82% of those polled supported a comprehensive approach, and 68% favored instruction on how to use a condom; only 36% supported abstinence-only programs.

In these tight budget times, we are pleased that the President's FY11 budget increased funding for the new teen pregnancy prevention initiative by \$19.2 million, for a total of \$133.7 million. We urge the committee to fund the initiative at least at the President's requested level of \$133.7 million. We are also pleased that the President's budget has once again included zero dedicated funding for failed abstinence-only-until-marriage programs, and we encourage the Committee not to include funding for these ineffective programs.

Congress should continue to act in the best interest of young people by supporting public health and education policies that are comprehensive, rooted in the best science, and reflect mainstream values.

HIV Prevention at the Centers for Disease Control and Prevention (CDC)

President Obama proposed an increase of \$31 million for HIV prevention programs at the Centers for Disease Control and Prevention (CDC). While we are grateful for this proposed increase during such difficult economic times, this amount is far from what is needed to reduce the number of new infections in the United States, which still stands at over 56,000 per year. State and local health departments and community-based organizations need increased resources to strengthen and expand outreach, education, HIV testing, and prevention programs targeting high-risk populations. The CDC believes that in order to adequately address the HIV epidemic in this nation, an additional \$878 million is needed over each of the next five years. We are requesting an increase of \$878 million for a total of \$1.6 billion for CDC HIV prevention activities in FY 2011.

With increased funding, other crucial prevention efforts can be augmented such as the delivery and evaluation of behavioral interventions, social marketing campaigns, surveillance, and other preventative education programs. Community based organizations and state and local health departments are all facing severe financial challenges. Through budget cuts, hiring freezes, layoffs, and furloughs, health departments across the nation continue to curtail core public health functions including those that prevent the spread of HIV and other infectious diseases. Additional federal resources are absolutely necessary if we are to reverse the increase of new infections. Investing in HIV prevention will result in billions of dollars in reduced healthcare costs in the future. Moreover, given the strong epidemiological link between HIV and other STDs, including high rates of co-infection among certain populations such as African Americans and men who have sex with men, an increased investment in STD programs (through the Division of STD Prevention) is an essential component of scaling up HIV prevention efforts. The cost of treating new cases of HIV each year that is attributable to Chlamydia, gonorrhea, syphilis, and genital herpes is over \$1 billion per year.

We also request an increase of \$20 million, for a total of \$60.2 million, for the Division of Adolescent and School Health's HIV Prevention Education. Recent estimates suggest that while representing 25% of the ever sexually active population, 15-24 year-olds acquire nearly half of all new STDs. Each year, one in four sexually active teenagers contracts a sexually transmitted disease. In addition, nearly 15 percent of the 56,000 annual new cases of HIV infections in the United States occurred in youth ages 13 through 24 in 2006. This means that an average of one young person every hour of every day is infected with HIV in the United States. It is essential

that we provide schools with the resources they require to build and strengthen their capacity to improve child and adolescent health.

Title X Family Planning Program at the Office of Population Affairs

We request that funding for the Title X family planning program be increased to \$700 million over the next five years, beginning with an increase of \$76.5 million in fiscal year (FY) 2011. Title X is a vital part of our nation's health care infrastructure. The Institute of Medicine (IOM), in their recent review of the program, found Title X to be a "valuable program" providing "critical services" to those in need, but also noted that the program is not currently receiving the funds needed to fulfill its mission. As the Administration and Congress work to reform our health care system, the President has stated that we must build on what works. Title X is a prime example of the type of successful programs that should be expanded. We appreciate the President's leadership in providing a \$10 million increase for Title X in his FY 2011 Budget Request. However, in spite of the program's critical role and proven effectiveness, funding for Title X continues to fall well short of what is needed.

Title X serves nearly five million low-income women and men at more than 4,500 health centers each year. Title X services help women and men plan the number and timing of their pregnancies, thereby helping to prevent nearly one million unintended pregnancies each year, nearly half of which would otherwise end in abortion. In addition to providing contraceptive services and supplies, Title X health centers provide basic preventive health services, education, and counseling. For example, in 2007, Title X centers provided 2.2 million Pap tests and 2.4 million clinical breast exams. Not only do the services provided through Title X promote public health, they also save tax dollars. For every public dollar invested in Title X, \$4.02 is saved in Medicaid-related costs alone.

Conclusion

We urge you to include in the Labor-HHS-Education appropriations bill the strongest possible teen pregnancy prevention and sex education initiative that will meet the needs of all young people and help them achieve healthier and safer lives. We also urge you to adequately fund HIV prevention at the CDC and the Title X family planning program so that the health goals of our nation can be met. If we can answer any questions or provide the Committee with any additional information, do not hesitate to be in touch with Jen Heitel Yakush, Director of Public Policy at SIECUS, at jyakush@siecus.org or 202.265.2405.

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Simmons Bedding Co., 20100 S. Alameda St., Compton, CA 90221

April 15, 2010

Subcommittee on Labor, Health and Human Services, Education and Related
Agencies
Committee on Appropriations
2358-C Rayburn House Office Building
Washington, D.C. 20515

Dear Members of the House Appropriations Committee:

In response to your federal Register Notice 75:2890-2891 entitled OSHA Listens: Occupational Safety and Health Administration Stakeholder Meeting, I would like to take this opportunity to speak up against the idea of a fee-based Voluntary Protection Programs (VPP). I believe that this will be detrimental to the integrity of the program and the culture of a safe workplace beyond compliance that it currently instills.

On behalf of our 120 associates in our facility and more than 3,000 associates throughout North America, we appreciate this to provide meaningful feedback on how we believe OSHA can most effectively allocate your limited resources to improve the safety and health of our associates.

We highly recommend you reallocate more resources for the Voluntary Protection Program (VPP) within your Cooperative Programs. VPP has been the single most effective tool we have ever seen in bringing our union workers and managers together to develop innovative ways to identify and address workplace hazards.

Under the leadership and direction of our Corporate Director of HR - Safety, Health, Wellness & Workers' Compensation – Jonathan J. Dawe, Ph.D., we consulted with OSHA a year ago and during our first VPP onsite evaluation at our facility in Compton, CA. the OSHA Team Leader identified several physical hazards opportunities during his walkthrough inspection; this was included in the report as an area needing improvement. As a result of that finding, our associates put together a corrective action plan,

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which essentially eliminated unsafe working conditions in the plant and is now used elsewhere throughout the network.

Developing a safety culture in a workplace than used to be a "second class" in our operations has been challenging. Since the partnership that we have developed with OSHA, furthermore, with the Journey of obtaining VPP class has been pivotal in our plant performance as a whole. One of the area that we like the most of the program is that the elements of VPP far exceed existing regulatory standards and require continuous improvement and goal setting. As a result, participants are constantly improving policies and procedures well beyond OSHA standards.

We will like to ask OSHA to maintain adequate OSHA staffing in the various Cooperative Programs to support the increasing number of onsite VPP evaluations being requested. We have discovered through the implementation of VPP, it is one of the most effective ways to develop a safety culture that works.

Thank you for the opportunity to provide comments to this worthwhile undertaking. We as a company are fully committed to the Elimination of all injuries in our workplace and believe VPP is the most effective health and safety management system in the world to get us there.

Respectfully,

Santiago Lampon,
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**The Society for Healthcare Epidemiology of America (SHEA)
Statement on Fiscal Year 2011 Funding for the U.S. Department of Health and Human Services
(HHS), the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH)
and the Agency for Healthcare Research and Quality (AHRQ)**

The Society for Healthcare Epidemiology of America (SHEA) appreciates this opportunity to express its support for federal efforts to prevent and reduce healthcare-associated infections. SHEA was founded in 1980 to advance the application of the science of healthcare epidemiology. The Society works to achieve the highest quality of patient care and healthcare personnel safety in all healthcare settings by applying epidemiologic principles and prevention strategies to a wide range of quality-of-care issues. SHEA is a growing organization, strengthened by its membership in all branches of medicine, public health, and healthcare epidemiology.

SHEA and its members are committed to implementing evidence-based strategies to prevent healthcare-associated infections (HAIs). SHEA members have scientific expertise in evaluating potential strategies for eliminating preventable HAIs. We collaborate with a wide range of infection prevention and infectious diseases societies, specialty medical societies in other fields, quality improvement organizations, and patient safety organizations in order to identify and disseminate evidence-based practices.

Our principal partners in the private sector are sister societies such as the Infectious Diseases Society of America (IDSA) and the Association of Professionals in Infection Control and Epidemiology (APIC). The Centers for Disease Control and Prevention (CDC), its Division of Healthcare Quality Promotion (DHQP) and the federal Healthcare Infection Practices Advisory Committee (HICPAC), and the Council of State and Territorial Epidemiologists (CSTE) have been invaluable federal partners in the development of guidelines for the prevention and control of HAIs and in their support of translational research designed to bring evidence-based practices to patient care. Further, collaboration between experts in the field (epidemiologists and infection preventionists), CDC and the Agency for Healthcare Research and Quality (AHRQ) plays a critical role in defining and prioritizing the research agenda. In 2008, SHEA aligned with the Joint Commission and the American Hospital Association to produce and promote the implementation of evidence-based recommendations in the *Compendium of Strategies to Prevent Healthcare-Associated Infections in Acute Care Hospitals* (<http://www.shea-online.org/about/compendium.cfm>). The Society also contributes expert scientific advice to quality improvement organizations such as the Institute for Healthcare Improvement (IHI), the National Quality Forum (NQF), and state-based task forces focused on infection prevention and public reporting issues.

SHEA applauds the Congress for its support of HAI prevention and reduction activities through the American Recovery and Reinvestment Act (ARRA) in 2009. The Society continues to collaborate with the Department of Health and Human Services (HHS) and the CDC to translate agency goals and objectives for HAI funds into actions at the bedside that can achieve meaningful reductions in preventable HAIs. However, there is a critical need for ongoing congressional support of a national prevention strategy to address a problem estimated by CDC to be one of the top ten causes of death in the nation and one that poses a significant economic burden on the nation's healthcare system.

Centers for Disease Control and Prevention (CDC)

The CDC plays a critical role in public health protection through its health promotion, prevention, preparedness and research activities. As you consider FY 2011 funding levels for the CDC, **SHEA urges**

your support of at least \$8.8 billion for CDC's "core programs" to ensure that the agency is able to carry out its prevention mission and to assure an adequate translation of new research into effective state and local programs. CDC's leadership was especially critical in efforts to provide support and guidance to state and local health departments as well as the public in its response to the 2009 H1N1 influenza virus. In addition to maintaining a strong public health infrastructure and protecting Americans from public health threats and emergencies, SHEA strongly believes that CDC programs play a vital role in reducing healthcare costs, improving the public's health, and providing much-needed unbiased education on HAIs and their prevention.

SHEA is particularly concerned about CDC's Infectious Diseases program budget, which supports critical management and coordination functions for infectious diseases research, policy development, and intervention programs including related specific epidemiology and laboratory activities. **SHEA recommends an FY 2011 funding level of \$2.3 billion for CDC's Infectious Diseases programs.**

Within the Emerging and Zoonotic Infectious Disease programs' proposed budget, the agency's **Antimicrobial Resistance budget would be cut dramatically by \$8.6 million**, or just over 50 percent. This vital program is necessary to help combat the rising crisis of drug resistance, one of the most pressing problems and greatest challenges that healthcare providers will confront during the coming decade. As bacteria and other micro-organisms are becoming more resistant to antimicrobials, our current therapeutic options are dwindling and research and development of new antibiotics is lagging. For the first time since the discovery and introduction of penicillin in the 1940s, we are dangerously close to a return to the pre-antibiotic era.

Antimicrobial resistance is a very real problem that extends to every segment of the healthcare community. Yet the President's FY2011 budget would allow only 20 state/local health departments and health care systems to be funded for surveillance, prevention, and control of antimicrobial resistance, down from 48 this past year. It would also eliminate all grants to states for the successful Get Smart in the Community program to combat improper uses of antibiotics. These cuts would be devastating at a time when we need to be fully committed to the goals of antimicrobial stewardship, to the research needed to define the most effective interventions and to educating the next generation of stewards.

CDC's antimicrobial resistance activities including state-based and local surveillance and educational initiatives are so critical to protecting Americans from serious and life-threatening infections that SHEA urges you to **double funding for CDC's antimicrobial resistance activities to at least \$40 million in FY 2011.**

The Society strongly **supports the proposed FY 2011 increase of \$12.3 million in the Preparedness, Detection and Control of Infectious Diseases line item to allow for the expansion of the National Healthcare Safety Network (NHSN) from 2,500 to 5,000 hospitals.** SHEA believes that protecting and improving resources for implementation of programs that standardize measurement of appropriate HAI outcomes and performance measures should be a priority. Our most valuable resource in this regard is NHSN, a voluntary, secure, internet-based surveillance system that integrates and expands patient and healthcare personnel safety surveillance systems. Many states consider NHSN to be the best option for implementing standardized reporting of HAI data. It is an enormously important national resource and effective funding and support is essential to expand its implementation. The proposed increase will allow CDC to build on progress made with FY 2009 ARRA funds to leverage the NHSN and support the dissemination of HHS evidence-based practices within hospitals to reduce these infections and save lives.

These funds are also intended to allow CDC to build the workforce capacity, laboratory facilities, and skills sets within State and local health departments to enhance the ability to detect and control emerging infectious diseases. It should be noted that this funding level is not sufficient to sustain the NHSN and State and local health department activities in this area.

The Society urges you to **increase the funding for CDC's budget line for Emerging Infections by \$25 million in FY 2011**. In FY 2010, \$11.7 million of this budget line were allocated to the Division of Healthcare Quality and Promotion. The additional \$25 million should be used to support State and local health department HAI surveillance and prevention activities and provide a means for sustaining and expanding the important HAI initiatives that have been started using ARRA funds. Given the condition of State economies, it is unlikely that State funding will be available and the benefits of most programs will be lost at the end of 2011 without continued federal support. As we seek to strengthen our public health infrastructure and reorient our health system toward prevention and preparedness, a strong federal role should be part of a comprehensive approach to reduce HAIs and costs in line with the goals of health care reform.

On a related note, recognizing that currently 21 states mandate the use of NHSN for state public reporting and this number is expected to grow, immediate efforts should be made to enable interfaces between electronic health records (EHRs) and NHSN. In this way, additional burdens are not placed upon healthcare entities from either an infection prevention and control or information technology (IT) perspective as the desirability for national database integration proceeds.

SHEA is pleased with the proposed establishment and funding (\$10 million) of a new workforce program, the Health Prevention Corps, within the CDC to enhance the capacity of the public health infrastructure to respond to current and emerging health threats. This program is intended to recruit new talent for state/local health departments with a focus on disciplines with known workforce shortages, such as epidemiology. This investment is very timely, as a recently released report from the CSTE documented a 10 percent decline in the number of state-based epidemiologists over the last three years, with a 40 percent deficit in the overall number of epidemiologists needed for full capacity across the 50 states. Clearly, our ability to reduce and prevent HAIs is highly dependent upon a continued strong investment in hospital infrastructure and qualified personnel for infection prevention and control.

National Institutes of Health (NIH)

SHEA is very pleased that ARRA infused the NIH with billions of dollars for research projects that will enable growth and investment in biomedical research and development, public health and health care delivery. The NIH is the single-largest funding source for infectious diseases research in the US and the life-source for many academic research centers. The NIH-funded work conducted at these centers lays the ground work for advancements in treatments, cures, and medical technologies. We applaud Congress for acknowledging the impact of scientific research in stimulating the economy. It is critical that we maintain this momentum for medical research capacity. Accordingly, **SHEA supports an overall funding level of \$35 billion for NIH in FY 2011**.

While SHEA is very pleased with the proposed major investment in Agency for Healthcare Research and Quality (AHRQ) for research focused on HAIs (discussed below), support for basic, translational, and epidemiological HAI research has not been a priority of the NIH. Despite the fact that HAIs are among the top ten annual causes of death in the US, scientists studying these infections have received relatively less

funding than colleagues in many other disciplines. In 2008, NIH estimated that it spent more than \$2.9 billion dollars on funding for HIV/AIDS research, approximately \$2.0 billion on cardiovascular disease research, about \$664 million on obesity research and, by comparison, National Institute of Allergy and Infectious Diseases (NIAID) provided \$18 million for MRSA research. SHEA believes that as the magnitude of the HAI problem becomes part of the dialogue on health care reform, it is imperative that the Congress and funding organizations put significant resources behind this momentum.

The limited availability of federal funding to study HAIs has the effect of steering young investigators interested in pursuing research on HAIs toward other, better-funded fields. While industry funding is available, the potential conflicts of interest, particularly in the area of infection-prevention technologies, make this option seriously problematic. These challenges are limiting professional interest in the field and hampering the clinical research enterprise at a time when it should be expanding.

Our discipline is faced with the need to bundle, implement and adhere to interventions we believe to be successful while simultaneously conducting basic, epidemiological, pathogenetic and translational studies that are needed to move our discipline to the next level of evidence-based patient safety. The current convergence of scientific, public and legislative interest in reducing rates of HAIs can provide the necessary momentum to address and answer important questions in HAI research. SHEA strongly urges you to **enhance NIH funding for FY 2011 to ensure adequate support for the research foundation that holds the key to addressing the multifaceted challenges presented by HAIs.**

Agency for Healthcare Research and Quality (AHRQ)

SHEA strongly supports the proposed investment of \$34 million by AHRQ in FY 2011 to reduce and prevent healthcare-associated infections (HAIs). Funds made available through AHRQ (and CDC) should be used, in part, for translational research projects that can allow more rapid integration of science into practice. As an example, this could involve use of funds to support positions through which large collaboratives could be supported in states not currently part of AHRQ or Health Research and Educational Trust (HRET) projects (for example, Public Health Research Institute (PHRI) and Keystone, which have achieved successful reductions in device-associated infections). Experts in the field (Epidemiologists and Infection Preventionists), in collaboration with CDC and the AHRQ, should be engaged in order to further define and prioritize the research agenda. As we strive to eliminate all preventable HAIs, we need to identify the gaps in our understanding of what is actually preventable. This distinction is critical to help guide subsequent research priorities and to help set realistic expectations. SHEA believes in the importance of conducting basic, epidemiological and translational studies (to fill basic and clinical science gaps). While health services research (i.e., successful implementation of strategies already known or suspected to be beneficial) may provide some immediate short-term benefit, to achieve further success, a substantial investment in basic science, translational medicine, and epidemiology is needed to permit effective and precise interventions that prevent HAIs.

SHEA thanks the committee for this opportunity to share our priorities with respect to Fiscal Year 2011 funding for HHS, CDC, NIH and AHRQ. The Society is pleased to serve as a resource to the committee going forward on issues related to healthcare epidemiology.

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Written Statement
Joshua Copel, M.D., President
Society for Maternal-Fetal Medicine

Contact: Patricia Stahr, Executive Director
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to the
House Subcommittee on Labor, Health and Human Services and Education
on behalf of the
Eunice Kennedy Shriver National Institute of Child Health and
Human Development Fiscal Year 2011 Budget
April 16, 2010

Mr. Chairman and Members of the Committee –

The Society for Maternal-Fetal Medicine is pleased to have the opportunity to submit testimony in support of the FY 2011 budget for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). We are grateful for your strong and sustained commitment to the National Institutes of Health, in particular the NICHD. Through the programs of the NICHD, ground-breaking research advances have been made that have changed the practice of obstetrics.

Established in 1977, the Society for Maternal-Fetal Medicine (SMFM) is dedicated to improving maternal and child outcomes; and raising the standards of prevention, diagnosis, and treatment of maternal and fetal disease.

Maternal-fetal medicine specialists, also known as MFM specialists, perinatologists, and high-risk pregnancy physicians, are highly trained obstetricians/gynecologists with advanced expertise in obstetric, medical, and surgical complications of pregnancy and their effects on the mother and fetus. The complex problems faced by these mothers may lead to death or problems, both short-term and life-long for both the mothers and their babies. Only through research can complications involving the mother or unborn fetus be understood, treated, prevented and eventually solved.

The mission of NICHD is to ensure that every child is born healthy and that women suffer no harmful effects from reproductive processes. NICHD supports a blend of basic, clinical, translational, and multidisciplinary research studies that address a myriad of issues in pregnancy such as:

- **Preterm birth:** Preterm birth (delivery before 37 weeks' gestation) is associated with increased risks of death in the immediate newborn period as well as in infancy, and can cause long-term complications including devastating disabilities. About 20% of premature babies die within the first year of life, and although the survival rate is improving, many preterm babies have life-long disabilities, including cerebral palsy, mental retardation, respiratory problems, and hearing and vision impairment. Preterm birth occurs in nearly 13% of all deliveries in the United States, a higher rate than in other developed countries (5-9%). The

total cost of preterm birth in the United States is \$26 billion a year, according to a 2006 report of the Institute of Medicine.

- **Stillbirth:** Stillbirth defined as the death of a fetus at 20 or more weeks of gestation, complicated nearly 26,000 pregnancies in the United States in 2005. Considerable racial disparity exists—stillbirth is more than twice as common among African Americans than Caucasian women (11.1 versus 4.8 per 1,000). Other maternal risk factors for stillbirth include advanced age, obesity, and co-existing medical disorders such as diabetes or hypertension. The possible impact of environmental exposures on stillbirth risk remains unknown. Of known stillbirth causes, the most common are genetic abnormalities, alterations in the number or structure of the chromosomes, maternal infection, hemorrhage, and problems with the umbilical cord or placenta. However, the cause remains unknown in about half of all stillbirths.
- **Hypertensive diseases in pregnancy:** High blood pressure (hypertension) during pregnancy endangers the health of both the mother and the baby and is increasingly common as women delay pregnancy until they are older, and as they are more frequently overweight. Hypertension in pregnancy is the second leading cause of maternal death in the United States, accounting for 15% of all deaths. For the mother, it is associated with early delivery, increased need for labor induction because of pregnancy complications, stroke, pulmonary or heart failure, and death. The likelihood and severity of these complications increases as the severity of the hypertension increases, and if preeclampsia develops. Preeclampsia is characterized by high blood pressure and the presence of protein in the urine. Its cause, or causes, remains one of the greatest mysteries in obstetrics and is a major cause of maternal, fetal, and neonatal mortality worldwide.
- **Pregestational and gestational diabetes:** The hormonal changes of pregnancy can seriously worsen preexisting diabetes and often bring about a diabetic state (gestational diabetes) in predisposed women. Whether diabetes mellitus existed before conception or gestational diabetes develops during pregnancy, maternal glucose intolerance can have significant medical consequences for both mother and baby. Poorly controlled diabetes is associated with miscarriage, congenital malformations, abnormal fetal growth, stillbirth, obstructed labor, increased cesarean delivery, and neonatal complications. Up to 200,000 pregnancies are affected by gestational diabetes each year.

Great strides are being made through NICHD-supported research to address the complex situations faced by mothers and their babies. One of the most successful approaches for testing research questions related to preterm birth is the NICHD research networks, which allow researchers from across the country to coordinate their work and share data. The networks deal with different aspects of the problem of preterm birth and its consequence. For example:

- **Stillbirth Collaborative Research Network:** The NICHD established the Stillbirth Collaborative Research Network (SCRN) to study the extent and causes of stillbirth in the United States. The SCRN is conducting a geographic population-based determination of the incidence of stillbirth and is determining the causes of stillbirth using a standardized protocol that includes clinical histories, autopsies and pathologic examinations of the fetus and placenta as well as other postmortem tests to illuminate genetic, maternal and environmental influences. The information that is now coming from this Network will benefit families who

have experienced a stillbirth, women who are pregnant or who are considering pregnancy, and obstetric care providers. In addition, the knowledge gained from this Network will support future research aimed at improving preventive and therapeutic interventions and at understanding the mechanisms that lead to fetal death.

- **Maternal-Fetal Medicine Units Network:** To achieve a greater understanding and pursue development of effective treatments for the prevention of preterm births, low birth weight infants and medical complications during pregnancy, in 1986 the NICHD established the Maternal-Fetal Medicine Units Network (MFMU). The MFMU Network has changed obstetrical practice by identifying new effective therapies and putting an end to practices that are not useful. It is the only national research infrastructure capable of performing the much needed large trials that provide the evidence on which sound medical practice is based. The MFMU Network is also the ideal vehicle to collaborate with other NIH networks, as well as international networks in order to improve global health. Since its inception, the Network has made several exciting scientific advancements and has been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures that directly benefit those affected.
 - A major advance in the prevention of preterm birth has been the use of progesterone in the second and third trimesters, which resulted in a substantial reduction in the rate of preterm delivery among women who had a previous preterm birth and also reduced the risk of newborn complications. The annual savings of preventing recurrent preterm delivery by progesterone treatment in the U.S. has been estimated at more than \$2 billion. Research into progesterone use in women with other risk factors is continuing. So far studies have shown that progesterone treatment is not effective in twin or triplet pregnancies, but it may reduce the rate of preterm birth in women with a short cervix. If effective for this indication, progesterone treatment would be particularly helpful for identifying women at risk in their first pregnancy. On-going study is needed to identify the optimal populations for treatment and the best treatment regimens.
 - A significant development in clinical care, antenatal corticosteroid administration promotes fetal lung maturity. It is one of the most effective means of preventing newborn complications, including respiratory distress, intraventricular hemorrhage, and death, when preterm birth occurs. Though a single course of treatment is effective if given before preterm birth, the effect appears to decline over time if the pregnancy remains undelivered. Research over the past decade has shown that repeated doses of antenatal corticosteroids, either weekly or on alternate weeks, is associated with negative effects on fetal growth that could potentially outweigh their benefits. Current research is evaluating the potential benefits of a single “rescue course” of corticosteroids for undelivered women who have a second episode of threatened preterm delivery.
 - Large trials have suggested that magnesium sulfate treatment, given when preterm delivery is expected before 32-34 weeks, results in a reduction in cerebral palsy. Because cerebral palsy is the most prevalent chronic motor disability, with an estimated lifetime cost of nearly \$1 million per individual, its prevention is of great significance to patients, their family and to society. While current evidence is encouraging, further study is needed to determine the optimal treatment regimen and which pregnancies would benefit most from this intervention.

Though novel and important research areas have emerged to improve the outcomes of mothers and babies, there are still many challenges that face us:

- ***Translation of Genomics and Proteomics into Preterm Birth and Stillbirth*** – Preterm birth and stillbirth represent two of the most important complications of pregnancy. Prevention of preterm birth and stillbirth depends on identifying women at risk and understanding the mechanisms of disease. It is imperative that NICHD take advantage of high throughput technologies to understand the causes of preterm birth and stillbirth and support genomics, proteomics, and metabolomics studies focusing on prediction and prevention of preterm birth and stillbirth, as well as the use of existing biobanks. The promise of these new technologies is that a better understanding of the biologic processes involved in pregnancy and pregnancy complications will lead to improved prediction, prevention, and treatment strategies that will improve maternal and infant health.
- ***Severe, early adverse pregnancy outcomes*** – Women with severe, early adverse pregnancy outcome, such as multiple losses, demises, and severe preeclampsia, are at increased risk for long-term chronic health problems, including hypertension, stroke, diabetes, and obesity. Studies have shown that women who have had preeclampsia are more likely to develop chronic hypertension, to die from cardiovascular disease and to require cardiac surgery later in life. In addition, approximately 50% of women with gestational diabetes will develop diabetes later in life. Pregnancy can be considered as a window to future health and the immediate post-pregnancy period provides a unique opportunity for prevention of chronic diseases later in life. Studies to identify women at risk for long term morbidity, and to develop strategies to prevent long term adverse outcomes in these women are urgently needed.
- ***Maternal Fetal Medicine Units Network*** – Vigorous support of the MFMU Network is needed so that therapies and preventive strategies that have significant impact on the health of mothers and their babies will not be delayed. Until new options are created for identifying those at risk and developing cause specific interventions, preterm birth will remain one of the most pressing problems in obstetrics.

As the Committee moves forward with deliberations on the fiscal year 2011 budget, we urge you to provide greater resources to the National Institutes of Health, and in particular to the National Institute of Child Health and Human Development. Research is the cornerstone for improving our understanding of the physiology and pathophysiology of pregnancy, the interrelationship between the mother and fetus, the impact of medical conditions on pregnancy and the impact of medical diseases and pregnancy outcomes on the long term health of both mother and child. With your support, researchers can continue to peel away the layers of complex problems of pregnancy that have such devastating consequences.

RECOMMENDATIONS:

The Society for Maternal Fetal Medicine recommends:

- An appropriation of \$35 billion for the National Institutes of Health in FY2011.
- A funding level of \$1.5 billion for the National Institute of Child Health and Human Development.

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- NICHD sustain the research investment in the MFMU Network to facilitate resolution of the myriad of problems that affect high risk mothers and their fetuses.
- NICHD support genomics, proteomics, and metabolomics studies focusing on prediction and prevention of preterm birth and stillbirth.
- NICHD identify women at risk for long-term morbidity and develop strategies to prevent long-term adverse outcomes.

Thank you for the opportunity to present our views.



SOCIETY FOR PUBLIC HEALTH EDUCATION
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Public Record Testimony of the Society for Public Health Education

Regarding FY 2011 Funding for Disease Prevention and Wellness Programs

Presented to the
 United States House of Representatives Committee on Appropriations
 Subcommittee on Labor, Health and Human Services, Education and Related
 Agencies

April 16, 2010

The Society for Public Health Education (SOPHE) is a professional health education organization founded in 1950 to promote the health of all people by stimulating research on the theory and practice of health behavior; translating sound science into practice; and supporting high quality standards for professional preparation. SOPHE is the only independent professional organization devoted exclusively to health education and health promotion. SOPHE's 4000 national and chapter members work daily to improve health outcomes and promote wellness in a variety of settings, including schools, universities, health care organizations, corporations, voluntary health agencies and federal, state and local government. There are currently 20 SOPHE chapters covering more than 30 states and regions across the country.

SOPHE's broad membership enables us to advocate and understand the need for increased resources targeted at the most pressing public health issues. For the FY 2011 funding cycle, SOPHE encourages the Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) Subcommittee to increase funding for public health programs that focus on preventing chronic disease and other illnesses; eliminating health disparities; and promoting the coordinated school health model. In particular, SOPHE would like to request the following FY 2011 funding levels for Labor-HHS programs:

- **\$969.854 million for the National Center for Chronic Disease Prevention and Health Promotion;**
- **\$50 million for the CDC REACH (Racial and Ethnic Approaches to Community Health) program;**
- **\$77.64 million for CDC DASH (Division of Adolescent and School Health), \$33.9 million of which shall be specifically appropriated for the coordinated school health program; and**

- **\$30 million for the CDC Healthy Communities Program.**

SOPHE gratefully acknowledges the strong bipartisan support that the House Subcommittee on Labor, Health and Human Services and Education has provided to the Centers for Disease Control and Prevention (CDC) in recent years, including the funding dedicated to the Prevention and Wellness Fund in the American Recovery and Reinvestment Act of 2009. The field of health education and health promotion, which is some 100 years old, uses sound science to plan, implement, and evaluate interventions that enable individuals, groups, and communities to achieve personal, environmental and population health. There is a robust, scientific evidence-base documenting not only that various health education interventions work but that they are also cost-effective. These principles serve as the basis for our support for the programs outlined below.

Preventing Chronic Disease

The data are clear: chronic diseases are the nation's leading causes of morbidity and mortality and account for 75 percent of every dollar spent on health care in the U.S. Collectively, they account for 70 percent of all deaths nationwide. Thus, it is highly likely that 3 of 4 persons living in the districts of the Labor-HHS Subcommittee members will develop a chronic condition requiring long-term and costly medical intervention in their lifetime. In 2008, heart disease and stroke were estimated to cost \$448 billion in medical expenditures and lost productivity. In 2009, U.S. healthcare expenditures exceeded \$7,200 for every man, woman, and child, primarily for diagnosis and treatment of chronic diseases.

SOPHE is requesting a FY 2011 funding level of \$937 million for CDC's National Center for Chronic Disease Prevention and Health Promotion in order to adequately address the cost of chronic disease care and prevent it from further burdening our nation's citizens and productivity. NCCDPHP is at the forefront of the U.S. efforts to prevent and control chronic diseases. The Center was substantially cut in 2006, and then has essentially been level-funded and has decreasing resources due to across the board rescissions – while chronic disease rates have continued to soar.

Studies show that spending as little as \$10 per person on proven preventive interventions could save the country over \$16 billion in just five years. The public overwhelmingly supports increased funding for disease prevention and health promotion programs. Small investments now in community-led, innovative programs will help to increase our nation's productivity and performance in the global market; decrease rates of infant mortality, deaths due to cancer, cardiovascular disease, diabetes, and HIV/AIDS, and; increase immunization rates.

SOPHE is requesting a FY 2011 funding level of \$30 million for CDC's Healthy Communities Program to advance policy and environmental change strategies in support of healthy eating, active living, and chronic disease and obesity prevention. Through the Healthy Communities Program, CDC collaborates with local and state health and park departments, national organizations with extensive community outreach, and community leaders to prevent chronic disease. Among the many successes of the program since its inception are restoring physical education to the school day; requiring physical activity and healthy snacks in child care sites; changing zoning requirements to include sidewalks to promote physical activity; and enhancing farmers markets and community gardens to for wider access to fruits and vegetables.

Chronic disease prevention programs, like those delivered by NCCDPHP, are especially needed among our nation's youth. In the last 20 years, the percentage of overweight youth has more than doubled, and for the first time in two centuries, children may have a shorter life expectancy than their parents. Fifteen percent of children and adolescents are overweight and more than half of these children have at least one cardiovascular disease risk factor, such as elevated cholesterol or high blood pressure. Almost 80 percent of young people do not eat the recommended five servings of fruits and vegetables each day. Daily participation in high school physical education classes dropped from 42 percent in 1991 to 32 percent in 2001. Patterns of poor nutrition, lack of physical activity, and other behaviors such as alcohol and tobacco use established during youth often continue into adulthood and contribute markedly to costly, chronic conditions.

CDC's Coordinated School Health Programs have been shown to be cost-effective in improving children's health, their behavior, and their academic success. This funding builds bridges between state education and public health departments to coordinate health education, nutritious meals, physical education, mental health counseling, health services, healthy school

environments, health promotion of faculty, and parent and community involvement. Gallup polls show strong parental, teacher, and public support for school health education.

SOPHE urges this subcommittee to support an appropriation of \$33.9 million in FY 2010 for CDC's Division of Adolescent and School Health, Coordinated School Health

Programs. In 2008, 43 states (plus five tribal governments and four territorial education agencies) applied for such funding; however, because of limited resources, only 22 states and 1 tribal government were funded. A funding level of \$33.9 million would allow capacity building grants to an additional of up to 17 states (from 23 to 40).

Chronic diseases account also for the largest health gap among populations and increase health disparities among racial and ethnic minority groups. As the U.S. population becomes increasingly diverse, the nation's health status will be heavily influenced by the morbidity of racial and ethnic minority communities. African Americans, Alaskan Natives, American Indians, Asian Americans, Hispanic Americans, and Pacific Islanders are more likely than whites to have poorer health and to die prematurely, especially from chronic conditions.

SOPHE strongly urges an allocation of \$50 million for CDC's Racial and Ethnic Approaches to Community Health Across the U.S. (REACH U.S.) initiative to eliminate health disparities among urban and rural communities in the areas of cardiovascular disease, immunizations, breast and cervical cancer screening and management, diabetes, HIV infections/AIDS, and infant mortality. A funding level of \$50 million would allow for the distribution of monies to support at least 10 two-year planning grants for communities to implement evidence- and practice-based approaches to reducing chronic disease rates.

Launched in 2007, REACH U.S. is the next evolution of REACH 2010, which was developed by HHS and CDC to find "out of the box" community-driven solutions to address health disparities. REACH U.S. is unique because it works across public and private sectors to conduct community based prevention research and demonstration projects that address social determinants of health. REACH U.S. programs are time-tested, community-led interventions that have proven success in decreasing health disparities. President Obama highlighted a need to address health disparities in

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his FY 2011 Budget Blueprint, and with increased funding REACH U.S. programs can address his call to action.

Thank you for this opportunity to present our views to this Subcommittee. We look forward to working with you to improve the health and quality of life for all Americans.

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**Before the House Appropriations Subcommittee on Labor, Health and Human Services,
Education, and Other Related Agencies
March 15, 2010
Submitted for the Record**

On the behalf of the Society for Women's Health Research (SWHR) and the Women's Health Research Coalition (WHRC), we are pleased to submit the following testimony in support of federal funding of biomedical research, and specifically women's health research.

The Society for Women's Health Research (SWHR), a national non-profit organization based in Washington DC, is widely recognized as the thought leader in research on sex differences and is dedicated to improving women's health through advocacy, education, and research. SWHR was founded in 1990 by a group of physicians, medical researchers and health advocates who wanted to bring attention to the myriad of diseases and conditions that affect women uniquely.

In 1999, the WHRC was established by SWHR to give a voice to scientists and researchers from across the country that are committed to improving women's health research. WHRC now has more than 650 members, including leaders within the scientific community and medical researchers from many of the country's leading universities and medical centers, as well as leading voluntary health associations, and pharmaceutical and biotechnology companies.

SWHR and WHRC are committed to advancing the health of women through the discovery of new, targeted scientific knowledge. We believe that sustained funding for biomedical and women's health research programs conducted and supported across the federal agencies is absolutely essential if we are to meet the health needs of women, and men, and advance the nation's research capability.

In this testimony we address the clinical successes and financial hardships of five key agencies and subgroups doing the important work of sex-based research: **National Institutes of Health (NIH)**, **NIH's Office of Research on Women's Health (ORWH)**, **Health and Human Services' Office of Women's Health (HHS)**, **the Centers for Disease Control and Prevention (CDC)**, and **the Agency for Healthcare and Research Quality (AHRQ)**. If America wants to remain a leader in health care advancement, if we are serious about the advancement of personalized medicine, if we are ready to stop wasting health care dollars on inappropriate treatments or the costs that come with guessing versus knowing—then we implore Congress to supply these agencies with the tools needed to accomplish these goals.

National Institutes of Health

Past Congressional investment and support for NIH has positioned the United States as the world leader in biomedical research and has provided a direct and significant impact on women's health research and the careers of women scientists over the last decade. The 111th Congress saw

the importance of increasing funds to NIH in the 2009 American Recovery and Reinvestment Act. This funding is having an enormous impact on research and research facilities throughout the United States, creating new jobs, new innovations and improved technologies. However, the U.S.'s position as world leaders in biomedical research is threatened by a budget that does not continue to provide significant funding to NIH. Flat-lining NIH funding, or worse, cutting funds and not keeping up with inflation, threatens the developments started by ARRA, and puts the innovative research practices and reputation that America is known for in jeopardy.

When faced with budget cuts, NIH has shown that it is left with no other option but to reduce the number of grants it is able to fund. When not including the one-time ARRA infusion of funds, the number of new grants funded by NIH had dropped steadily with budgets growing at less than that of inflation since FY2003. A shrinking pool of available grants has a significant impact on scientists who depend upon NIH support to cover both salaries and laboratory expenses to conduct high quality biomedical research, putting both medical advancement and job creation at risk. Failure to obtain a grant decreases publishing of new finds and decreases the number of scientists gaining experience in research, both reducing a scientist's likelihood of achieving tenure in a university setting. New and less established researchers are forced to consider other careers, the end result being the loss in academia of the skilled bench scientists and researchers so desperately needed to sustain America's cutting edge in biomedical research.

SWHR recommends Congress to set a laudable goal of reaching \$40 billion in NIH funding in the next three years. To meet this goal, SWHR urges you to exceed the Administration's FY 2011 request of a \$1 billion increase and to allocate an additional \$3 billion in funding for the NIH in FY2011, resulting in a total research budget of \$34 billion.

In addition, SWHR requests that Congress strongly encourage the NIH to utilize ARRA funding as well as appropriated dollars to ensure that women's health research receives resources sufficient to meet the health needs of all women. SWHR further recommends that NIH, with the funds provided, report sex differences in all research findings. With the tools the NIH already has available, it should seek to expand its inclusion of women in basic, clinical and medical research to Phase I, II, and III studies. By currently only mandating sufficient female subjects in Phase III, science misses out on the chance to look for variability by sex in the early phases of research, where scientists look at treatment safety and determine safe dose levels for new medications. By raising the bar, NIH can continue to serve as a role model for industry research, as well as other nations. Only by gaining more information on how therapies work in women will medicine be able to advance more targeted and effective treatments for all patients, men and women alike.

Only within the past decade have scientists begun to uncover significant biological and physiological differences between women and men, as it impacts health and medicine. Sex-based biology, the study of biological and physiological differences between women and men, has revolutionized the way that the scientific community views the sexes. Sex differences play an important role in disease susceptibility, prevalence, time of onset and severity and are evident in cancer, obesity, heart disease, immune dysfunction, mental health disorders, and many other illnesses. Medications can have different effects in woman and men, based on sex specific differences in absorption, distribution, metabolism and elimination. It is imperative that research addressing these important differences be supported and encouraged. Congress clearly recognizes these important sex differences and NIH should as well.

Office of Research on Women's Health

The NIH's Office of Research on Women's Health (ORWH) has a fundamental role in coordinating women's health research at NIH: advising the NIH Director on matters relating to research on women's health and sex and gender research; strengthening and enhancing research related to diseases, disorders, and conditions that affect women; working to ensure that women are appropriately represented in research studies supported by NIH; and developing opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. ORWH is currently implementing recommendations from the NIH working group on Women in Biomedical Careers to maximize the potential of female biomedical scientists and engineers in both the NIH and external research community.

Two highly successful programs supported by ORWH that are critical to furthering the advancement of women's health research are Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCOR). The BIRCWH program, created in 2000, is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. SCORs, established in 2003, are designed to increase the transfer of basic research findings into clinical practice by housing laboratory and clinical studies under one roof. These programs benefit the health of both women and men through sex and gender research, interdisciplinary scientific collaboration, and provide tremendously important support for young investigators in a mentored environment. Each BIRCWH receives approximately \$500,000 a year, most of which comes from the ORWH budget but is also supported by many NIH Institutes and Centers. Each SCOR program costs \$1 million per year and results in unique research.

Additionally, Advancing Novel Science in Women's Health Research (ANSWHR) was created by ORWH in 2007 to promote innovative new concepts and interdisciplinary research in women's health research and sex/gender differences. ORWH also has the Research Enhancement Awards Program (REAP) to support meritorious research on women's health that just missed the IC pay line and a Partnership with the National Library of Medicine to identify overarching themes, specific health topics, and research initiatives into women's health. ORWH, through successful collaboration with the NIH ICs, provides research funding for: breast cancer, HPV vaccines, uterine leiomyoma, vulvodynia, irritable bowel syndrome, stroke, substance abuse, eating disorders including obesity, menopause, microbicides, chronic pain syndromes, autoimmune disorders, muscular skeletal disorders, and health disparities among many other issues.

In order for ORWH's programs and research grants to continue to expand and thrive, Congress must direct that NIH continue its support of ORWH and **provide it with \$2 million dollar budget increase, bringing its FY2011 total to \$44.9 million..**

Health and Human Services' Office of Women's Health

The HHS Office of Women's Health (OWH) is the government's champion and focal point for women's health issues. It works to redress inequities in research, health care services, and education that have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would and will be only more difficult and delayed.

Under HHS, several agencies have federal offices specific to women's health. Agencies currently with offices, advisors or coordinators for women's health or women's health research include the Food and Drug Administration, Centers for Disease Control and Prevention, Agency for Healthcare Quality and Research, Indian Health Service, Substance Abuse and Mental Health Services Administration, Health Resources and Services Administration, and Centers for Medicare and Medicaid Services. It is imperative that these offices are funded at levels adequate for them to perform their assigned missions, and are sustainable so as to support needed changes in the long term. We ask that the Committee Report reflect Congress's supports of the permanent existence of these various federal women's health offices, **recommending that they are appropriately funded on a permanent basis** to ensure that these programs can continue and be strengthened in the coming fiscal year.

It is only through continued and increased funding that the OWH will be able to achieve its goals. The budget for FY2010, as in recent years, flatlined OWH budget at \$33.7 million. This was, in essence, a decrease, due to inflation. Considering the amount and impact of **women's health programs from OWH, we urge Congress to provide an increase of \$2 million for the HHS OWH, a total \$35.7 million requested for FY2011.**

Centers for Disease Control and Prevention

SWHR supports the national and international work of the CDC, and especially the work of CDC's Office of Women's Health. While aware of unavoidable cuts in many sectors of the FY2011 budget, SWHR is concerned that the proposed CDC budget cuts and project eliminations jeopardize a number of programs that benefit women, leaving them with even fewer options for sound clinical information. Research and clinical medicine are still catching up from decades of a male-centric focus, and when diseases strike women, there is a paucity of basic knowledge on how diseases affect female biology, a lack of drugs that have been adequately tested in women, and now even fewer options for information through the many educational outreach programs of the CDC.

Cutting funding for programs on **blood disorders**, specifically for von Willebrand's disease, which has disproportionate impact on women, ending awareness campaigns on **gynecological cancers** funded by Johanna's Law, and eliminating specific funds dedicated to projects on **Inflammatory Bowel Disease and Interstitial Cystitis (IC)** will all result in women losing an advocate and a partner in advancing women's health. The proposed cuts to IC programs, in particular, equate to a loss of approximately half of its budget. These reductions translate to more than just a significant cut in total CDC budget. They create losses in jobs and in advocacy efforts led by patients suffering from these diseases, particularly IC, and their advocacy organizations, eliminating important education toward diagnosis and treatment. **SWHR hopes that there will be serious consideration of the impact eliminating these programs will have on women, and men, who suffer these diseases, and encourages reviewing alternate sources of funding as a means to continue these important programs.** The total savings realized by eliminating these programs is less than 1/2 of 1% of the total programmatic resources budget for the CDC, and their elimination will have ramifications on patients and providers, as well as incalculable effects on advocacy groups, jobs, and information campaigns.

Agency for Healthcare and Research Quality

The Agency for Healthcare Research and Quality's work serves as a catalyst for change by promoting the results of research findings and incorporating those findings into improvements in the delivery and financing of health care. Through AHRQ's research projects, lives have been

saved. For example, it was AHRQ who first discovered that women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines, which have improved diagnostic accuracy and dramatically increased the timely use of “clot-dissolving” medications in women having heart attacks.

While AHRQ has made great strides in women’s health research, its budget has been dismally funded for years, though targeted funding increases in recent years for dedicated projects, including funds from ARRA, are moving AHRQ in the right direction. However, more core funding is needed to help AHRQ continue doing the research that helps patients and doctors make better medical decisions.

AHRQ’s budget for FY2009 was \$372 million, \$397 million for FY2010. Such modest annual increases will not offer results that improve decision making by doctors and patients for improved health outcomes. This Agency has been operating under a major shortfall for years. Decreased funding seriously jeopardizes the research and quality improvement programs that Congress mandates from AHRQ. We recommend Congress fund AHRQ at the Administration’s proposed **\$611 million for FY2011**, an increase of \$214 million over the FY2010 level. The lion’s share of this increase will appropriately focus on patient-centered health research. This will ensure that adequate resources are available for high priority research, including women’s health care, sex and gender-based analyses, and health disparities—information that can help to better personalize treatments and improve outcomes for female and male patients nationwide.

Summary of Recommendations

| | |
|-------------------|--|
| NIH FY2011..... | Additional \$3 billion funding, \$34 billion total Increased focus on women’s health research Inclusion of women in all phases of NIH research |
| OWHR FY2011..... | Additional \$2 million funding, \$44.9 million total |
| HHS FY2011..... | Permanent funding of federal women’s health offices throughout HHS Additional \$2 million for OWH, \$35.7 million total |
| CDC FY2011 | Restored or alternate funding for 4 select projects |
| AHRQ FY2011 | Match the Administration’s proposed budget of \$611 million |

In conclusion, SWHR and the WHRC would like to thank the Chair and this Committee for its strong record of support for medical and health services research and its unwavering commitment to the health of the nation through its support of peer-reviewed research. We look forward to continuing to work with you to build a healthier future for all Americans.

**Spina Bifida Association and Spina Bifida Foundation
Written Testimony to the House Labor, Health and Human Services (LHHS)
Appropriations Subcommittee**

**Regarding Fiscal Year 2011 Spina Bifida Program Funding through the Department of
Health and Human Services: Centers for Disease Control and Prevention, Agency for
Healthcare Research and Quality, and National Institutes of Health**

**Submitted by: Scott T. Price, Esq., President,
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April 16, 2010

Funding Request Overview

The Spina Bifida Association (SBA) and the Spina Bifida Foundation (SBF) respectfully request that the Subcommittee provide the following allocations in Fiscal Year (FY) 2011 to help improve quality-of-life for people with Spina Bifida:

- \$7.5 million for the National Spina Bifida Program within the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) to support existing program initiatives and allow for the further development of the National Spina Bifida Patient Registry.
- \$5.126 million for the CDC's national folic acid education and promotion efforts to support the prevention of Spina Bifida and other neural tube defects.
- \$26.342 million to strengthen the CDC's National Birth Defects Prevention Network.
- \$163.5 million in overall funding for the CDC's National Center on Birth Defects and Developmental Disabilities.
- \$611 million for the Agency for Healthcare Research and Quality (AHRQ).
- \$32.2 billion for the National Institutes of Health (NIH) to support biomedical research.

Background and Overview

On behalf of the estimated more than 166,000 individuals and their families who are affected by all forms of Spina Bifida – the nation's most common, permanently disabling birth defect – SBA and SBF appreciate the opportunity to submit written testimony for the record regarding FY 2011 funding for the National Spina Bifida Program and other related Spina Bifida initiatives. SBA is a national voluntary health agency working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. The SBF assists SBA in its fundraising and advocacy efforts. SBA and SBF stand ready to work with Members of Congress and other stakeholders to ensure our nation mounts and sustains a comprehensive effort to reduce and prevent suffering from Spina Bifida.

Spina Bifida, a neural tube defect, occurs when the spinal cord fails to close properly within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy – as the fetus grows – the spinal cord is exposed to the amniotic fluid, which increasingly becomes toxic. It is believed that the exposure of the spinal cord to the

toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida occurring from mild – with little or no noticeable disability – to severe – with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this neural tube defect is that most people with it suffer from a host of physical, psychological, and educational challenges – including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls, which seeks to ameliorate their condition by helping to relieve cranial pressure associated with spinal fluid that does not flow properly. As we have testified previously, the good news is that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living into adulthood and increasingly into their advanced years. These gains in longevity, principally, are due to breakthroughs in research, combined with improvements generally in health care and treatment. However, with this extended life expectancy, our nation and people with Spina Bifida now face new challenges, such as transitioning from pediatric to adult health care providers, education, job training, independent living, health care for secondary conditions, and aging concerns, among others. Individuals and families affected by Spina Bifida face many challenges – physical, emotional, and financial. Fortunately, with the creation of the National Spina Bifida Program in 2003, individuals and families affected by Spina Bifida now have a national resource that provides them with the support, information, and assistance they need and deserve.

As is discussed below, the daily consumption of 400 micrograms of folic acid by women of childbearing age, prior to becoming pregnant and throughout the first trimester of pregnancy, can help reduce the incidence of Spina Bifida, by up to 70 percent. However, 3,000 pregnancies are affected by Spina Bifida, resulting in 1,500 babies born each year with the condition, and, as such, with the aging of the Spina Bifida population and a steady number of affected births annually, the nation must take additional steps to ensure that all individuals living with this complex birth defect can live full, healthy, and productive lives.

Cost of Spina Bifida

It is important to note that the lifetime costs associated with a typical case of Spina Bifida – including medical care, special education, therapy services, and loss of earnings – are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare programs. The emotional, financial, and physical toll and costs of Spina Bifida on the individuals and families affected are extraordinary. Efforts to reduce and prevent suffering from Spina Bifida will help to not only save money, but will also save – and improve – lives.

Improving Quality-of-Life through the National Spina Bifida Program

Since 2001, SBA has worked with Members of Congress and staff at the CDC to help improve our nation's efforts to prevent Spina Bifida and diminish suffering – and enhance quality-of-life

– for those currently living with this condition. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. The CDC’s National Spina Bifida Program works on two critical levels – to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. The program seeks to ensure that what is known by scientists is practiced and experienced by the individuals affected by Spina Bifida. Moreover, the National Spina Bifida Program works to improve the outlook for a life challenged by this complicated birth defect – principally, identifying valuable therapies from in-utero throughout the lifespan and making them available and accessible to those in need.

The National Spina Bifida Program established the National Spina Bifida Resource Center housed at the SBA, which provides information and support to help ensure that individuals, families, and other caregivers, such as health professionals, have the most up-to-date information about effective interventions for the myriad primary and secondary conditions associated with Spina Bifida. Among many other activities, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, such as bladder and bowel control difficulties, learning disabilities, depression, latex allergies, obesity, skin breakdown, and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. All of these problems can be treated or prevented, but only if those affected by Spina Bifida – and their caregivers – are properly educated and given the skills and information they need to maintain the highest level of health and well-being possible. The National Spina Bifida Program’s secondary prevention activities represent a tangible quality-of-life difference to the 166,000 individuals living with all forms of Spina Bifida, with the goal being living well with Spina Bifida.

An important resource to better determine best clinical practices and the most cost effective treatments for Spina Bifida is the National Spina Bifida Registry, now in its second year. Nine sites throughout the nation are collecting patient data, which supports the creation of quality measures and will assist in improving clinical research that will truly save lives, while also realizing a significant cost savings.

In FY 2010, SBA requested that \$7 million be allocated to support and expand the National Spina Bifida Program. In the final FY 2010 Omnibus Appropriations Act, Congress provided \$6.242 million for this program, a slight increase following three years of essentially flat funding. SBA understands that the Congress and the nation face unprecedented budgetary challenges and, as such, appreciates this modest increase. However, the progress being made by the National Spina Bifida Program must be sustained and expanded to ensure that people with Spina Bifida – over the course of their lifespan – have the support and access to quality care they need and deserve. To that end, SBA respectfully urges the Subcommittee to Congress allocate \$7.5 million in FY 2011 to the program so it can continue and expand its current scope of work; further develop the National Spina Bifida Patient Registry; and sustain the National Spina Bifida Resource Center. Increasing funding for the National Spina Bifida Program will help ensure that our nation continues to mount a comprehensive effort to prevent and reduce suffering from – and the costs of – Spina Bifida.

Preventing Spina Bifida

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty-five million women of child-bearing age are at-risk of having a child born with Spina Bifida. As mentioned above, the daily consumption of 400 micrograms of folic acid prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce the incidence of Spina Bifida, by up to 70 percent. There are few public health challenges that our nation can tackle and conquer by nearly three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 30 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age – particularly those most at-risk for a Spina Bifida pregnancy – consume adequate amounts of folic acid prior to becoming pregnant.

Since 1968, the CDC has led the nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain a diet rich in folic acid. This public health success should be celebrated, but still too many women of childbearing age consume inadequate daily amounts of folic acid prior to becoming pregnant, and too many pregnancies are still affected by this devastating birth defect. The nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call – such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

SBA is the managing agent for the National Council on Folic Acid, a multi-sector partnership reaching more than 100 million people a year with the folic acid message. The goal is to increase awareness of the benefits of folic acid, particularly for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves, or those who have already conceived a baby with Spina Bifida). With additional funding in FY 2011, CDC's folic acid awareness activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBA advocates that Congress provide additional funding to CDC to allow for a targeted public health education and awareness focus on at-risk populations (e.g., Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.

In addition to a \$7.5 million FY 2011 allocation for the National Spina Bifida Program, SBA urges the Subcommittee to provide \$5.126 million for the CDC's national folic acid education and promotion efforts to support the prevention of Spina Bifida and other neural tube defects; \$26.342 million to strengthen the CDC's National Birth Defects Prevention Network; and \$163.5 million to fund the National Center on Birth Defects and Developmental Disabilities.

Improving Health Care for Individuals with Spina Bifida

As you know, AHRQ's mission is to improve the outcomes and quality of health care, reduce health care costs, improve patient safety, decrease medical errors, and broaden access to essential health services. AHRQ's work is vital to the evaluation of new treatments, which helps ensure that individuals living with Spina Bifida continue to receive state-of-the-art care and interventions. To that end, we request a \$611 million FY 2011 allocation for AHRQ, so it can continue to provide guidance and support to the National Spina Bifida Patient Registry and help improve quality of care and outcomes for people with Spina Bifida.

Sustain and Seize Spina Bifida Research Opportunities

Our nation has benefited immensely from our past federal investment in biomedical research at the NIH. SBA joins with other in the public health and research community in advocating that NIH receive increased funding in FY 2011. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA respectfully requests that the Subcommittee include language in the report accompanying the FY 2011 LHHS appropriations measure:

- Urging the National Institute of Child Health and Human Development (NICHD) to continue to support – and expand – a more comprehensive Spina Bifida research portfolio that focuses on addressing the myriad secondary effects and conditions associated with Spina Bifida;
- Commending the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for exploring issues related to the neurogenic bladder and encouraging the institute to forge ahead with its work in this important topic area; and
- Encouraging the National Institute of Neurological Diseases and Stroke (NINDS) to continue and expand its research related to the treatment and management of hydrocephalus.

Conclusion

Please know that SBA and SBF stand ready to work with the Subcommittee and other Members of Congress to advance policies and programs that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views regarding FY 2011 funding for programs that will improve the quality-of-life for the 166,000 Americans and their families living with all forms of Spina Bifida.

**TESTIMONY FOR THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON
LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION:
FY 2011 FUNDING FOR ALCOHOL AND DRUG PREVENTION, TREATMENT,
RECOVERY AND RESEARCH PROGRAMS**

Submitted by Gabrielle de la Gueronniere, Director for National Policy, Legal Action Center, on
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April 16, 2010

State Associations of Addiction Services (SAAS) and the Legal Action Center (LAC) appreciate the opportunity to submit testimony on FY 2011 funding for substance use prevention and addiction treatment, recovery, and research programs. SAAS is a national organization representing state provider associations and community-based alcohol and drug abuse prevention and addiction treatment programs in 43 states. The mission of SAAS is to ensure the availability and accessibility of quality drug and alcohol treatment, prevention, education, and research programming. The Legal Action Center is a non-profit law and policy organization that works to expand services for people with alcohol and/or drug addictions, people living with HIV/AIDS, and people with criminal records.

**FIELD RECOMMENDATIONS FOR SUBSTANCE USE PREVENTION, AND ADDICTION TREATMENT,
RECOVERY SUPPORTS AND RESEARCH FUNDING FOR FY 2011**

The unmet need for alcohol and drug treatment services in America is overwhelming, with only 10% of the more than 23 million Americans in need actually receiving care. Strategies and programs proven effective in preventing alcohol and drug problems reach far too few of our young people. We respectfully request that Congress increase funding for key alcohol and drug programs in order to meet this incredible need. In partnership with other prevention and treatment advocates, we urge Congress to adopt the following funding levels in FY 2011 for alcohol and drug prevention, treatment, and recovery and research programs in the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Institutes of Health. These investments will provide desperately needed services in communities across the country:

- **\$2.0085 billion** for the Substance Abuse Prevention and Treatment Block Grant
- **\$529.6 million** for the Center for Substance Abuse Treatment (CSAT)
- **\$277.2 million** for the Center for Substance Abuse Prevention (CSAP)
- **\$522.4 million** for the National Institute on Alcohol Abuse and Alcoholism (NIAAA)
- **\$1.1976 billion** for the National Institute on Drug Abuse (NIDA)

**ADDICTION IS AN ILLNESS THAT CAN BE PREVENTED AND TREATED WITH SERVICES THAT WORK
AND SAVE MONEY**

Numerous studies have demonstrated the effectiveness of substance abuse prevention and addiction treatment services in reducing alcohol and drug addiction and use. Addiction treatment has been shown to cut drug use in half, reduce crime by 80 percent and reduce arrests up to 64 percent. Addiction treatment is also sustainable; treatment is significantly associated with a 67 percent reduction in weekly cocaine use, a 65 percent reduction in weekly heroin use, a 52 percent decrease in heavy alcohol use, a 61 percent reduction in illegal activity, and a 46 percent decrease in suicidal

ideation one year post treatment. Moreover, these outcomes are generally stable for the same clients five years post treatment.

Prevention also has been shown to be effective in reducing alcohol and drug use and the risk of addiction, and in improving academic achievement. A recent University of Washington study found that the level of peer substance use in schools has a substantial impact on academic performance; students whose peers avoided substance use had test scores that were on average 18 points higher for reading, and 45 points higher for math. The Center for Substance Abuse Prevention (CSAP) has identified numerous models of prevention programs backed by research findings of effectiveness that empower communities to meet their unique needs.

In addition to reducing drug use, treatment and prevention are cost-effective. According to SAMHSA, for every dollar the United States Government spends on addiction treatment it saves \$7 to \$25 in other costs. A number of state studies have also demonstrated the cost-effectiveness of treatment and prevention. One study found that in Ohio, every \$1 spent on addiction treatment saved \$11 in other health care costs. A Washington state study showed a 50 percent decrease in all other medical expenses for those receiving treatment. In Minnesota, a recent study showed that one year after alcohol and drug treatment, 67 percent of investment from reductions in all other health care costs was recovered. In addition, a Washington state study of school-based prevention programs found that a number of these programs resulted in a \$70.34 benefit for each dollar of programming spent for each participating young person. These savings resulted from increased productivity and reduced health care, criminal justice, and social services costs.

CLOSING THE ADDICTION TREATMENT GAP

Alcohol and drug addiction is a preventable and treatable disease – just like cancer, diabetes, and heart disease. People with addictions can and do recover and have a meaningful life in the community, if they get the help they need. However, while addiction afflicts almost one in ten Americans and affects one of every four children, only *9.9% of the 23.1 million* people who need treatment for alcohol and drug problems receive it.

According to SAMHSA, in 2008 23.1 million Americans, or 9.9 percent of the population aged 12 or older, needed treatment for an illicit drug or alcohol use problem. Of these, just 2.3 million individuals received treatment at a specialty facility, leaving 20.8 million persons in need of these life-saving services.

Passage of the Wellstone/Domenici Mental Health Parity and Addiction Equity Act and the Patient Protection and Affordable Care Act presents a tremendous opportunity to ensure that many more Americans receive the addiction treatment care they need to enter into recovery. However, as these laws are implemented over the next several years, it is extremely important that critical safety net programs such as the Substance Abuse Prevention and Treatment Block Grant continue to receive the strongest possible federal support to close the addiction treatment gap. Those resources will remain vitally important, as a bridge to when health reform takes effect, and beyond in order to provide services to those who remain uninsured as well to support prevention and recovery support and other services not covered by private and public insurance.

We are encouraged by the proposed initiatives aimed at improving collaboration between the addiction treatment and primary care systems to close the addiction treatment gap. Efforts to educate and train primary care professionals about addiction, treatment and recovery need to be strengthened. In crafting initiatives to better integrate addiction treatment into the primary care system, such as the Federally Qualified Health Centers and Indian Health Service proposals in the FY 2011 budget, we urge the Committee to work to ensure that:

- Coordination among the federal agencies of jurisdiction, the single state authorities for substance abuse, and the community-based addiction treatment system is required.
- Community-based addiction service providers have a strong, clear role as these initiatives are developed.
- There is sufficient funding to support the additional individuals who are identified in the primary care system as needing addiction treatment and referred into the community-based addiction treatment system to receive care.

In addition, as providers of addiction treatment services work to strengthen existing or institute new health information technology systems, we urge the Committee to support the President's budget request for funding through the Office of the National Coordinator for Health Information Technology (ONC) for these purposes. This is particularly important since addiction service providers were not eligible for health information technology funds appropriated in the Recovery Act.

ENSURING OUR NATION'S YOUTH RECEIVE THE PREVENTION STRATEGIES AND SERVICES THEY NEED

It is also essential that we invest in our nation's youth by ensuring that they have access to quality substance abuse prevention and addiction treatment services. Currently millions of young people never benefit from proven substance abuse prevention strategies that are successful and cost-effective.

Alcohol remains the most heavily abused substance by America's youth. Although there has been a significant decline in tobacco and illicit drug use among teens, underage drinking has remained at consistently high levels. In addition, although rates for non-medical prescription drug use among adults are largely unchanged the past year, these rates have risen for young adults.

With the zeroing out of the Safe and Drug Free Schools and Communities (SDFSC) State Grants Program, the only federal money for drug and violence prevention that went to every school district in the country, the country's school-based prevention infrastructure is at risk for complete elimination. Without additional federal investment, millions of American children will be left without any drug prevention education and thousands of jobs around the country will also be eliminated.

We urge the Committee to ensure that any Department of Education school climate prevention programs that receive funding in the FY 2011 budget have an explicit, required focus on drug and alcohol use prevention. Without continued universal prevention, we will lose the gains that we have made in preventing tobacco and illicit drug use and will increase the risk for higher alcohol abuse.

THE ENTIRE CONTINUUM OF PREVENTION, TREATMENT, AND RESEARCH PROGRAMMING MUST BE ADEQUATELY FUNDED

We urge Congress to improve access to, and the effectiveness of, life-saving drug and alcohol services and research by increasing support for the following programs:

▪ **\$2.0085 billion for the Substance Abuse Prevention and Treatment Block Grant**

Funding for the Substance Abuse Prevention and Treatment (SAPT) Block Grant, the foundation of the publicly supported prevention and treatment system in this country, received level funding or cuts over the past several years. As the cornerstone of the nation's prevention and treatment system, the SAPT Block Grant must receive increased funding in order to meet current demand and increase access to services. SAMHSA's most recent data indicates that the SAPT Block Grant serves an average of 2 million people every year, providing a large part of all public funding for treatment services. Over 10,500 community-based organizations receive Block Grant funding from the states. The Block Grant also provides crucial support for the states' prevention programs, because of the required designation of 20 percent of the total funding for this purpose.

In many local jurisdictions, individuals can wait long periods before they are able to access appropriate drug and alcohol treatment. This access problem is caused in part by the fact that private and public insurance frequently do not cover the cost of treatment and states face unprecedented financial pressures, making treatment funding even more scarce and increasing the importance of the Block Grant. Funding the full continuum of services, including recovery supports, is extremely difficult for many jurisdictions given the limited amounts of funds that are available, the pressures facing other funding streams, such as Medicaid, and the restricted coverage provided by private insurance. Additional Block Grant funding would help alleviate the pressure on services and provide greater access to high-quality drug and alcohol prevention and treatment services.

▪ **\$529.6 million for the Center for Substance Abuse Treatment (CSAT)**

Although the FY 2011 administration budget proposes a \$32.4 million increase to CSAT, a more significant increase in funding for CSAT programming is essential to close the treatment gap. Funding for CSAT's Programs of Regional and National Significance supports States and communities to carry out an array of activities for service capacity expansion, service improvements and other priority needs. These programs are critical in order to ensure that what is learned about addiction through scientific research is effectively shared with the treatment provider community.

We also support the innovative approaches that SAMHSA has developed to expand the continuum of services offered and the range and capacity of providers. Peer recovery support services, provided through CSAT's Access to Recovery and Recovery Community Services Programs, are integral to recovery-oriented systems of care. We support building on these program's successes, including providing additional support for recovery support services critical to helping individuals stay healthy and drug-free.

In addition, funding for CSAT's portfolio that supports services that are tailored to address specific and emerging drug epidemics and/or underserved populations, such as youth, pregnant and parenting women, and communities of color must be strengthened. These CSAT funded services are critical and enable states and regions dealing with emerging needs, such as veterans returning home in need of essential addiction treatment services, to appropriately address them. We also urge support for CSAT's criminal justice programming and the Screening, Brief Intervention, and Referral to Treatment (SBIRT) program.

- **\$277.2 million for the Center for Substance Abuse Prevention (CSAP)**

Addiction is a disease that begins in adolescence; young people who start drinking before the age of 15 are five times more likely to have alcohol problems later in life than those who begin drinking at age 21 or older. Research by the National Institute on Drug Abuse (NIDA) has shown that if we can stop use and abuse before age 25, we will significantly reduce the prevalence of addiction. Prevention efforts are effective in deterring young people from using illicit drugs and alcohol.

We strongly support CSAP's Strategic Prevention Framework to promote the use of performance measurement by providers, expand collaboration across community agencies, and support implementation of effective prevention programs at the State and community levels. CSAP's Strategic Prevention Framework is helping communities to promote youth development, reduce risk-taking behaviors, build assets and resilience, and prevent problem behaviors across the life span and needs increased funding to continue and to expand its reach.

- **\$522.4 million for research at the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and \$1.1976 billion at the National Institute on Drug Abuse (NIDA)**

Research into the causes, costs, treatment, and prevention of alcoholism and drug addiction plays an essential role in improving the quality of services. Increasing the support available for research on drug and alcohol addiction would allow future research to focus on additional effective prevention strategies, medications development, and treatment and service delivery throughout the criminal justice system.

NIAAA and NIDA are both taking steps to promote the transfer of new research to practice, including collaboration with SAMHSA, state agencies and providers. Over the past several years, NIDA has made extraordinary scientific advances in understanding the nature of addiction, such as those made through the use of imaging technologies like positron emission tomography (PET scans), and through the development of the new treatment technologies and medications. Additionally, NIDA's Criminal Justice Drug Abuse Treatment Studies (CJ-DATS) research is designed to improve outcomes for people with substance use disorders by improving the integration of drug abuse treatment with other public health and public safety systems. Research on addiction as a disease has been useful in the development and testing of new science-based therapies. NIAAA also has conducted breakthrough research that has improved clinical practice, with much of this research focusing on the genetics, neurobiology, and environmental factors that underlie alcohol addiction. NIAAA also has sought to use new information about alcohol use to promote education and an effective public health response to this problem.

CONCLUSION

Our nation is spending only a fraction of what is necessary to prevent alcohol and drug abuse and treat addiction – a total of \$21 billion from all sources of funds, compared to social and economic costs estimated well in excess of \$350 billion. Public funding supports three-fourths of those expenditures, and funding appropriated by Congress is the critical foundation for prevention, treatment, recovery supports, and research. State Associations of Addiction Services and the Legal Action Center urge the Committee to approve the funding levels that we and other organizations in the field have recommended.

Thank you for your consideration.

**Telehealth Leadership Initiative
Labor, Health and Human Services, Education, and Related Agencies Appropriations
Subcommittee
Department of Health and Human Services
Office for the Advancement of Telehealth**

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The Telehealth Leadership Initiative (TLI) – a non-profit organization that represents the telehealth and e-health stakeholders before legislative, administrative, and judicial branches of local, state, and national governments and the entire telehealth community – appreciates the opportunity to submit written testimony to the House Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee. We respectfully request that the Subcommittee maintain last year’s funding levels and continue to provide \$11.6 million for the Office for the Advancement of Telehealth (OAT), in the FY 2011 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill. These resources will support access to quality health care services, through telehealth technologies, for remote, rural and underserved populations.

Telehealth Overview

Telehealth, also known as telemedicine, is the providing of health care, health information, and health education across a distance, using telecommunications technology, and specially adapted equipment. It allows physicians, nurses, and health care specialists to assess, diagnose and treat patients without requiring both individuals to be physically in the same location, regardless of whether that distance is across a street, across a city, across the state, or across continents.

There are many applications for telehealth, such as:

- Monitoring patients with chronic conditions or at-risk populations;
- Medical care for home-bound patients or those in rural, remote, or frontier locations;
- Mental telehealth for incarcerated populations;
- Access to medical care in areas with provider shortages;
- Access to health care services for those in correctional facilities and,
- Availability of expert consultations via satellite for individuals on the battlefield, cruise ships, space stations, research stations, and other inaccessible locations.

Telehealth has been used to successfully accomplish the following:

- Prevent unnecessary delays in receiving treatment;
- Reduce or eliminate travel expenses;
- Reduce or eliminate the separation of families during difficult and emotional times;
- Utilize the services of healthcare providers in locales where the supply of physicians may be adequate or at a surplus; and,
- Allow patients to spend less time in waiting rooms.

Currently, telehealth is practiced in many settings, such as rural hospitals, school districts, home-health settings, nursing homes, cruise ships, on the battlefield, and even on NASA space missions. Telehealth is well-established in certain disciplines, such as radiology and dermatology, and is being expanded in other disciplines, for example, home telehealth, mental telehealth, ocular telehealth, teledermatology, telepathology, telerehabilitation. It is being utilized further for specific populations, including individuals who are incarcerated or live or are stationed in remote locations.

OAT Overview

The Office for the Advancement of Telehealth (OAT), which is a grant making agency at the Department of Health and Human Services, is responsible for promoting the use of telehealth technologies for health care delivery, education, and health information services. Through its programs, OAT helps bring access to care to those living in remote, rural and underserved populations.

Requested Funding Levels for FY 2011

Over the years, telehealth has improved a patient's access to timely specialty care, reduced medical errors, and saved our health care system money. Last year, Congress funded telehealth initiatives at \$11.6 million for FY 2010. This year, the TLI urges the U.S. House of Representatives to maintain the same funding level for FY 2011.

We feel strongly that an \$11.6 million funding level for OAT is essential to ensuring that millions of Americans have access to quality health care services. Maintaining these funding levels will allow these programs to continue to work with and support communities, in their efforts to develop cost-effective uses of telehealth technologies.

These initiatives, carried out through OAT, are especially valuable in a time when millions of Americans are struggling to access quality health care services.

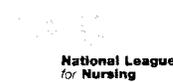
Credentialing and Privileging

In FY 2010, the Committee expressed its concern about a process soon to be enforced by the Centers for Medicare and Medicaid Services that would require all telemedicine originating sites where the patient is located to credential and privilege all telemedicine practitioners. For many small hospitals receiving telemedicine services, this could mean credentialing and privileging tens, if not hundreds, of telemedicine practitioners. It is a cost and personnel burden that essentially would force the closure of many telemedicine programs throughout the country. It is the single greatest threat to the expansion of telemedicine.

Since passage of the FY 2010 Appropriations, some positive developments have occurred. CMS has reached out to the telemedicine community and appears to be actively seeking a solution to the impact of this credentialing and privileging requirement. We urge the Committee to continue to exert its oversight on this issue to ensure that CMS develops a workable policy that does not cripple the delivery of telehealth services, while at the same time protects patient safety, a goal that the telehealth community shares with CMS.

Conclusion

Thank you for your attention to this important health care matter. We know you face many challenges in choosing funding priorities, but we hope you will continue to keep telehealth a priority and maintain last year's funding levels of \$11.6 million, in this year's FY 2011 appropriations' process. TLI appreciates the opportunity to share its views, and we thank you for your consideration of our request.



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Testimony of the Tri-Council for Nursing
Regarding FY 2011 Appropriations for Nursing Workforce Development Programs

Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

Department of Health and Human Services

April 15, 2010

The Tri-Council for Nursing, comprising the American Association of Colleges of Nursing, the American Nurses Association, the American Organization of Nurse Executives, and the National League for Nursing, respectfully requests \$267.3 million (a 10% increase) for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) in fiscal year (FY) 2011.

The Tri-Council is a long-standing alliance focused on leadership and excellence in the nursing profession. The nation is currently in the twelfth year of the nurse and nurse faculty shortages, contributing to a workforce deficit that diminishes the quality of patient care in the United States. As the nation looks towards reforming the healthcare system by focusing on expanding access, decreasing cost, and improving quality, a significant investment must be made in strengthening the nursing workforce.

In FY 2010, your Subcommittee provided a considerable funding boost for Title VIII that helped support the Loan Repayment and Scholarship program and Nurse Faculty Loan program. These increases will help bolster the pipeline of nurses and nurse faculty, which are so critical to reversing the nursing shortage. It is extremely important to maintain last year's funding level for these crucial programs in FY 2011. The Tri-Council believes the 10% requested increase should be directed to the four Title VIII programs that have not kept pace with inflation since FY 2005. These programs include the Advanced Education Nursing, Nursing Workforce Diversity, Nurse Education, Practice, and Retention, and Comprehensive Geriatric Education programs, which help expand nursing school capacity and increase patient access to care. The 10% increase awarded to these programs in proportion to their FY 2010 funding level would be a wise investment of federal resources.

Four Nursing Workforce Growth Areas: Critical Title VIII Programs that Provide Solutions

A Shortage of Providers Needed to Meet Increasing Healthcare Demands

With healthcare access expanded through the newly passed reforms, more providers will be needed. According to the U.S. Bureau of Labor Statistics (BLS), nursing is the nation's top profession in terms of projected job growth with more than 581,000 new nursing positions being created through 2018 (a 22% increase in the workforce). Moreover, healthcare professionals with knowledge and expertise in primary, transitional, and preventative care will be in great demand. Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs), and RNs with advanced education have the skills and are licensed to provide these vital services. The Advanced Education Nursing Grants and Traineeships help to educate the next generation of these providers in addition to the faculty who educate them.

Advanced Education Nursing (AEN) Grants (Sec. 811) support the preparation of RNs in master's and doctoral nursing programs. The AEN grants help to prepare our nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and other nurse specialists requiring advanced education. In FY 2008 (the most recent year for which data are available), these grants supported the education of 5,649 students.

- *AEN Traineeships* assist graduate nursing students by providing full or partial reimbursement for the costs of tuition, books, program fees, and reasonable living expenses. In FY 2008, this funding helped support 6,675 graduate nurses and APRNs.
- *Nurse Anesthetist Traineeships (NAT)* support the education of students in nurse anesthetist programs. In some states, Certified Registered Nurse Anesthetists (CRNAs) are the sole anesthesia providers in almost 100% of rural hospitals. Much like the AEN Traineeships, the NAT provides full or partial support for the costs of tuition, books, program fees, and reasonable living expenses. In FY 2008, the program supported 2,145 future CRNAs.

Increasing Nursing Diversity to Improve Patient Care

According to an April 2000 report prepared by the National Advisory Council on Nurse Education and Practice, a culturally diverse nursing workforce is essential to meeting the healthcare needs of the nation's population. However, the initial findings from the 2008 *National Sample Survey of Registered Nurses* show that while RN graduates entering the profession represent greater cultural diversity, when compared to the U.S. population, the profession still does not represent the current demographics of this country. Nurses from racial and ethnic minorities underrepresented in nursing contribute significantly to the provision of healthcare services and are leaders in the development of models of care that address the unique needs of our nation's populations. The Workforce Diversity Grants under Title VIII help to ensure a nursing workforce is developed to meet the healthcare needs of all patients.

Workforce Diversity Grants (Sec. 821) prepare students from disadvantaged backgrounds to become nurses. This program awards grants and contract opportunities to schools of nursing,

nurse-managed health centers, academic health centers, state or local governments, and nonprofit entities looking to increase access to nursing education for disadvantaged students, including racial and ethnic minorities underrepresented among RNs. In FY 2008, the program supported 11,638 students.

Education, Practice, and Retention: Enhancing and Maintaining the Knowledge Base of Nursing

Advances in healthcare technology, practice, and systems influence the way nurses deliver quality care. Like other health professions, nurses must continually expand their knowledge base to adapt to the changing healthcare environment. Higher learning and continued education for nurses are expected of all RNs as the profession strives for excellence in patient care. The Nurse Education, Practice, and Retention Grant program is designed to ensure RNs obtain additional knowledge in the discipline by expanding their entry-level education, improving their practice, and retaining seasoned clinicians in the profession.

Nurse Education, Practice, and Retention Grants (Sec. 831) help schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and healthcare facilities strengthen programs that provide nursing education. The three priority areas under this program help to:

- Expand the enrollment in baccalaureate nursing programs;
- Develop and implement internship and residency programs to encourage and mentor, as well as for the development of specialties;
- Provide education in new technologies, including distance learning methodologies;
- Establish or expand nursing practice arrangements in non-institutional settings to demonstrate methods to improve access to primary health care in medically underserved communities;
- Provide care for underserved populations and other high-risk groups such as older adults, individuals with HIV/AIDS, individuals with substance use disorders, people who are homeless, and those who are victims of domestic violence;
- Provide managed care, quality improvement, and other skills needed to practice in existing and emerging organized healthcare systems;
- Develop cultural competencies among nurses;
- Offer grants for career ladder programs to promote career advancement for nursing personnel and to assist individuals in obtaining education and training required to enter the nursing profession and advance within the profession; and
- Provide grants that enhance patient care delivery systems and are directly related to nursing activities by enhancing collaboration and communication among nurses and other healthcare professionals, and promote nurse involvement in the organizational and clinical decision-making processes of a healthcare facility.

In FY 2008, the priority areas under this program supported 42,761 nurses and nursing students.

Increased Nursing Care Needed for an Aging Population

Today, more than at any other time in our nation's history, nurses face an unprecedented

challenge—caring for an aging population that is growing at an exponential rate. According to the U.S. Census Bureau, 36.3 million Americans are over the age of 65, which represents 12% of the total population. It has been projected that by 2050, 86.5 million Americans will be over the age of 65. This represents a 147% increase between the years 2000 and 2050.

The National Center for Healthcare Statistics has reported that older adults account for 50% of hospital days, 60% of ambulatory adult primary care visits, 70% of all home care visits, and 85% of residents in nursing homes. Moreover, 63% of newly licensed nurses report that older adults comprise a majority of their patient loads. Clearly, more RNs are needed with expertise in geriatric nursing. The Comprehensive Geriatric Education Grants help to educate the next generation of these practitioners.

Comprehensive Geriatric Education Grants (Sec. 855) are awarded to schools of nursing or healthcare facilities to better provide nursing services for older adults. These grants are used to educate RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, prepare faculty members, and provide continuing education. In FY 2008, this program supported 6,514 nurses and nursing students.

With increased funding, these four programs can help address many issues currently impacting the nursing shortage. Therefore, the Tri-Council respectfully request \$267.3 million (a 10% increase) for the Nursing Workforce Development programs in FY 2011.

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Written Testimony of Jeffrey Levi, PhD
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House Appropriations Subcommittee on Labor, Health & Human Services, Education and
Related Agencies
Testimony Addresses the Centers for Disease Control & Prevention & the Office of the
Assistant Secretary for Preparedness & Response

My name is Jeff Levi, and I am Executive Director of Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority. I am grateful for the opportunity to submit testimony to the Subcommittee about public health appropriations.

As you craft the FY 2011 Labor, Health & Human Services, Education and Related Agencies appropriations bill, I hope that you will include robust funding for prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and the Office of the Assistant Secretary for Preparedness and Response (ASPR) in order to promote health and help protect Americans from natural and manmade threats and disasters. Moreover, as you work with the Department of Health and Human Services to allocate funding from the Prevention and Public Health Fund, I urge you to use this funding to support the long-term transformation of the nation's public health system.

Community Prevention

The U.S. spends more than any other nation in the world on health care costs but lags behind other nations in certain indicators of health. To improve health across the country, we must transform communities to remove barriers to healthy lifestyles and ensure that Americans have access to healthy environments, nutritious foods and venues for physical activity. TFAH was very pleased with the unprecedented investment that Congress and the Administration made in community prevention, through the American Recovery and Reinvestment Act (ARRA). Through ARRA's Communities Putting Prevention to Work Initiative, we will begin to see the seeds of transformation. In addition, programs at the Centers for Disease Control and Prevention (CDC), in particular Healthy Communities and Racial and Ethnic Approaches to Community Health Across the U.S. (REACH -U.S.), prioritize the health of communities and support innovative approaches to addressing disparities and improving health. In FY 2011, TFAH supports a total of \$52 million for the Healthy Communities Program and \$60 million for the REACH program to expand these successful programs to additional communities.

School Health

More than 23 million children in the U.S. are overweight or obese. To improve their health, we must reach them where they spend a great deal of time, and that includes schools. The Division of Adolescent and School Health's (DASH) Coordinated School Health Program provides funding to 22 states and one tribal government to strengthen the ability of state and local education agencies to address critical health issues, including obesity, asthma, tobacco use, HIV, STDs, and teen pregnancy, by building the capacity of funded partners to support science-based, cost-effective health programming. The President's FY 2011 budget proposes to increase

funding for DASH by \$3.875 million. TFAH strongly supports increased funding for DASH's School Health Program and hopes that at a minimum, the program will receive an additional \$20 million in FY 2011 to enable CDC to fund 15 additional state education agencies and 25 additional local education agencies to reach more children and youth through quality school health programs.

Pandemic Influenza

The recent H1N1 flu outbreak demonstrated how rapidly a new strain of flu can emerge and spread around the world. H1N1 provided a real-world test that showed our strengths and vulnerabilities to respond to a major infectious disease outbreak. Prior pandemic preparedness investments resulted in the development of medical countermeasures that have been used in the H1N1 response. In addition, supplemental appropriations have been used for response activities, including vaccine production, distribution and administration; antiviral drugs; surveillance; communications and community mitigation; and laboratory support for virus detection. TFAH supports continuing funding for our annual pandemic flu preparedness activities in FY 2011 at CDC (\$156 million), the National Institutes of Health (NIH) (\$35 million), the Food and Drug Administration (FDA) (\$45 million) and the Office of the Secretary (\$66 million) in order to strengthen our preparedness and response during any future outbreaks.

TFAH also urges appropriators to explore means to incorporate pandemic preparedness funds for state and local health departments into annual funding streams, such as the CDC Public Health Emergency Preparedness and ASPR Hospital Preparedness Program cooperative agreements. There is no annually recurring funding to support state and local pandemic preparedness. Yet, pandemic and all-hazards preparedness requires sustainable lab capacity, modernized disease surveillance systems, a well-trained workforce, effective medical countermeasures delivery and administration, surge capacity, and continuous exercising and improvement of response plans.

Another critical funding stream is the Biomedical Advanced Research and Development Authority (BARDA), which provides incentives and guidance for research and development of products to counter bioterrorism and pandemic flu. The President's budget proposes \$476 million for BARDA, with funding made available from current BioShield Special Reserve Fund balances. These funds would support research on countermeasures for biological threat agents, volatile nerve agents and radiological and nuclear threats. TFAH supports an increase in funding for BARDA and recommends that in FY 2011, at least \$500 million is provided, with the acknowledgement that higher levels of funding must ultimately be allocated and sustained.

Global Disease Detection (GDD)

Despite remarkable breakthroughs in medical research and advancements in immunization and treatments, infectious diseases are undergoing a global resurgence that threatens health. It is estimated that newly emerging and re-emerging infectious diseases will continue to kill at least 170,000 Americans annually. CDC's GDD Program helps recognize infectious disease outbreaks, improve the ability to control and prevent outbreaks, and detect emerging microbial threats. For FY 2011, TFAH recommends \$56 million for the GDD Program to enable CDC to increase the number of GDD centers and expand capacity at existing Centers. Funding would bring Thailand, Kenya, China and Guatemala to full capacity, support Egypt and Kazakhstan as basic centers and establish four additional developing centers.

Environmental Health

An additional area of interest for TFAH is the connection between our environment and our health. CDC's Environmental Health Laboratory performs biomonitoring measurements-- the direct measurement of people's exposure to toxic substances in the environment. By analyzing blood, urine, and tissues, scientists can measure actual levels of chemicals in people's bodies, and determine which population groups are at high risk for exposure and adverse health effects, assess public health interventions, and monitor exposure trends over time. TFAH supports an additional \$19.6 million for the Environmental Health Laboratory's biomonitoring capacity in FY 2011 in order to fund seven to ten grantees to conduct biomonitoring, increase the number of chemicals measured in CDC's *National Report on Human Exposure to Environmental Chemicals*, enable CDC to provide training and quality assurance for state laboratories awarded funds, and support the *National Report on Biochemical Indicators of Diet and Nutrition*.

Another important program, the National Environmental Health Tracking Network, enhances our understanding of the relationship between environmental exposures and the incidence and distribution of disease. The Tracking Network helps build our capacity to respond to environmental health issues and helps document links between environmental hazards and chronic disease. The National Network launched in July of 2009. CDC now funds just 22 states and one city to build and implement state-based tracking networks that will feed into the National Network. One additional state will be funded due to the increase in the Fiscal Year 2010 appropriations for this program. In order for the Network to be truly national in scope, it must be expanded to all states. To build toward that vision, TFAH recommends providing \$50 million for CDC's Environmental and Health Outcome Tracking Network to expand it to up to 13 additional grantees and support the continued development of a sustainable Network.

TFAH is also concerned about the potential health effects of climate change, including injuries and fatalities related to severe weather events and heat waves; infectious diseases; allergic symptoms; respiratory and cardiovascular disease; and nutritional and water shortages. TFAH was appreciative of the \$7.5 million included in FY 2010 for the Climate Change Program at CDC. To enable CDC to fund 20-25 states and localities for climate change needs assessment and planning, in addition to supporting other climate change preparedness activities, TFAH recommends at least \$15,000,000 for CDC's Climate Change Program in FY 2011. Ultimately, \$50 million is needed to develop a credible and effective Climate Change Program.

Public Health Workforce

A final area of critical importance to our nation's health is our public health workforce. The latest job loss survey by the National Association of County and City Health Officials (NACCHO) found that local health departments lost 8,000 jobs in the second half of 2009—compounding the loss of another 8,000 positions in the first half of the year. To address the workforce shortages in state and local health departments, the President's budget proposes a new workforce program, the Health Prevention Corps, which will recruit new talent into service for state and local health departments. The program will target disciplines with known shortages, such as epidemiology, environmental health and laboratory. FY 2011 funding would be used to establish a management plan for staffing and program administration, convene stakeholders to establish the program framework, and develop a curriculum for Corps members. TFAH supports the President's request of \$10 million for the Health Prevention Corps in FY 2011.

The Prevention and Public Health Fund

The Prevention and Public Health Fund, established by the Patient Protection and Affordable Care Act (P.L. 111-148), provides \$500 million in FY 2010 and \$750 million in FY 2011 for programs authorized by the Public Health Service Act for prevention, wellness, and public health activities. This funding should be used to support the long-term transformation of the nation's public health system. Investments from the Fund should be used in a manner that leverages change throughout the public health system – with a move away from a stove-piped, disease-by-disease approach to one that addresses the determinants of health in a cross-cutting manner.

The overarching goal should be to optimize the health of everyone by creating healthier, more resilient communities, through policy, systems, organizational, and environmental change. Investments from the Fund should be science informed or evidence based, have measurable health outcomes and policy goals, promote innovation, focus on the determinants of health and health equity, and be held accountable.

The National Prevention Strategy should become the basis for defining the goals of a transformed public health system, identifying gaps in the current system, and how the Fund can be used to help close these gaps.

Expenditure of Initial Funds

As the National Prevention Strategy is developed over the next year, expenditures under the Fund for FY 2010 and FY 2011 should be consistent with the following categories of expenditure, which were included in the House-passed bill. These include:

- Community Prevention: A focus on community prevention is the centerpiece of a transformed public health system. The focus should reflect cross-cutting approaches to reducing the risks that affect health and safety. In addition to chronic diseases, attention should be given to other critical health issues, such as injury and violence prevention, reproductive health, infectious diseases, emergency preparedness, mental health, birth defects and developmental disabilities, and environmental health. While state and local health departments must be central players in community prevention, grant funding is also needed to support the work of non-governmental organizations.
- Core Capacity (for both health departments and others doing community prevention): Health departments have varying levels of expertise and competency to design and manage community interventions that focus on policy, systems, organizational, and environmental change. All health departments should be supported in their efforts to expand the role of community prevention in addressing the health needs of their populations, but particular effort should be made to close the geographic gap in capacity to build healthier, safer, and more resilient communities. This can be done at least in part through the support of the accreditation process, which is focused on building these capacities and thresholds. Even with accreditation, we will need to provide funding to build a public health workforce able to serve in these accredited health departments.
- Research, Development, and Dissemination of Best Practices: There is a continuing need to expand the science base of prevention, with particular emphasis on translation into

practice and data to do appropriate program evaluation. This would include ramping up the capacity of the task forces on community and clinical prevention, creating the research and technical support for innovation in community prevention, and establishing the newly authorized program in public health services and systems research, with a particular emphasis on data collection and analysis.

Mr. Chairman, thank you again for the opportunity to submit testimony on the urgent need to enhance federal funding for public health programs which can save countless lives and protect our communities and our nation.



**Written Testimony Submitted to
The House Appropriations Committee, Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
By Michael L. Lomax, Ph.D., President and CEO of UNCF
May 19, 2010**

Mr. Chairman and distinguished Members of the subcommittee, I am Dr. Michael L. Lomax, President and CEO of UNCF – the United Negro College Fund. I want to thank you for allowing me to submit funding recommendations and priorities relevant to the FY11 Labor-HHS-Education Appropriations bill.

Before going forward, I would like to show my gratitude to the subcommittee for its historic support of historically black colleges and universities (HBCUs). Under the leadership of Chairman David R. Obey, this subcommittee has provided great support on the national forefront in appropriating funding for HBCUs and minority serving institutions (MSIs). Specifically, the efforts and accomplishment of securing \$850 million in mandatory funding through the Education and Health Reconciliation Act must be acknowledged. Through the efforts of this subcommittee and its illustrious Chairman, you have exhibited notable leadership in advancing the plight of a higher education for all Americans.

Statistically, HBCUs graduate a preponderant share of all black Americans receiving postsecondary degrees. While comprising only three percent of the nation's 4,197 institutions of higher learning, the 103 HBCUs are responsible for producing approximately 25% of all bachelor's degrees, 10% of all master's degrees and 26% of all first professional degrees earned by African Americans annually.

UNCF institutions are a critical component and significant subset of the larger community of HBCUs. Specifically, UNCF is the national fundraising and advocacy representative of 39 private historically black colleges and universities. There are more than 350,000 persons who are counted as alumni of UNCF member colleges and universities. Our alumni include persons such as Rev. Dr. Martin Luther King, Jr., Brown University President Dr. Ruth Simmons, three former surgeon generals, numerous current Members of Congress and a host of noted authors, poets, attorneys, professors and philanthropists.

UNCF- the nation's oldest and most successful minority higher education assistance organization fulfills its primary goal by increasing opportunities for access to higher education. During its 66-year existence, UNCF has raised more than \$3 billion to support its historically black college and university member institutions and administered nearly 300 programs, including scholarships, mentoring programs, summer enrichment, study abroad, curriculum, faculty, and leadership development. Today, UNCF supports more than 65,000 students at over 900 colleges and universities across the country.

UNCF was pleased to work with federal leaders throughout the 110th Congress to enact the Higher Education Opportunity Act (Public Law 110-315), thus completing the first reauthorization of the Higher Education Act in more than ten years. Anticipating economic challenges nationally, and the disproportionate impact of these challenges upon HBCUs and their students, UNCF advocated for increased authorized spending to support targeted institutional capacity building and federal student aid programs.

Expanded authorization to support existing programs, in addition to newly authorized activities cutting across the federal spectrum, are essential first steps towards a dramatic reinvestment in the institutions that will continue to produce the next generation of American workers and entrepreneurs.

We recognize that working with President Barack Obama's Administration and Congress will continue to be particularly challenging in a budget-constrained environment where more diverse students with unique academic and familial circumstances are dependent upon need-based aid. In keeping with this, UNCF continues to endorse the following policies and positions as the focal point of its legislative agenda for FY11. These recommendations continue a basic commitment to enrolling, nurturing, and graduating students, some of whom lack the social, educational, and financial advantages of other college bound populations. This agenda reflects what is needed to level the playing field for both UNCF member schools and students as we continue to pursue educational excellence.

The following FY11 programs authorized under Title III of the Higher Education Act (HEA) are of particular relevance and importance to UNCF.

- Title III, Part B, Strengthening Historically Black Colleges and Universities -- \$282 million (Section 323) and \$65 million (Section 326)

This program is continually the fundamental source of institutional assistance for HBCUs. The Title III, Part B program was first authorized and funded in FY87 and since its inception, has succeeded in supporting strategic planning initiatives, academic enhancements, administrative and fiscal management, student services, physical plant improvements, and general institutional development.

Significant increases in funding to Title III, Part B must be made over the next three years in order to enhance and sustain the quality of HBCUs, and to meet the national challenges associated with global competitiveness, job creation and changing demographics. For FY11, UNCF requests \$282 million to support Section 323 and \$65 millions for Section 326.

- Title III, Part D, HBCU Capital Financing Program -- \$21 million

Funded through Title III, Part D of the Higher Education Act, the HBCU Capital Financing Program is intended to provide low-interest capital financing loans to historically disadvantaged institutions throughout the HBCU community. In light of economic hardships and challenges confronting several of our member institutions, UNCF has worked with national stakeholders, officials at the Department of Education, and Congressional leadership to propose a comprehensive revision of the capital financing provisions.

For FY11, UNCF requests \$21 million to allow the Secretary to support the administration of additional loans through the Capital Financing Program. Further, we request the assistance of federal leaders in working with the HBCU Capital Financing Board to ensure that recommendations made to Congress will promote increased participation within the program among all eligible institutions.

UNCF and our member schools have, among them, many years of experience in making the dream of a college education a reality for low-income students and the colleges they attend. My staff and I, as well as the presidents of our member schools, stand ready to continue to work closely with this diligent committee to formulate and craft a plan that will work for all the young people who are seeking and deserving of a college education.

FY11 Funding Chart

| DEPARTMENT AGENCY PROGRAMS | FY10 PRESIDENT'S REQUEST | FY10 COALITION'S REQUEST | FY10 OMNIBUS | FY11 PRESIDENT'S REQUEST | FY11 COALITION REQUESTS |
|---|--|--------------------------|--|--|---------------------------------|
| DEPARTMENT OF EDUCATION STUDENT FINANCIAL ASSISTANCE | | | | | |
| Pell Grant (Maximum Award) | \$17.5 million (\$4,860 + ARRA= \$5,550) (CR p. 1319) | \$5,550 | \$17.5 million (\$4,860 + ARRA= \$5,550) (CR p. 1319) | (Ed.J. p. P-1) (\$5,710) (PE p. 385) | \$0 (\$5,710) \$1 billion |
| TRIO | \$848 million (CR p. 1321) | \$968 million | \$653.1 million (CR p. 1321) | \$653.1 million (Ed.J. p. U-16) | \$1 billion |
| Supplemental Educational Opportunity Grants | \$757 million (CR p. 1319) | \$1 billion | \$757.5 million (CR p. 1319) | \$757.5 million (Ed.J. p. Q-24) | \$1 billion |
| Leveraging Educational Assistance Partnership Program (LEAP) | \$64 million (CR p. 1319) | \$200 million | \$64 million (CR p. 1319) | \$0 (Ed.J. p. 31) | \$200 million |
| Federal Work Study | \$980 million (CR p. 1319) | TBD | \$980 million (CR p. 1319) | \$960 million (Ed.J. p. Q-24) | \$1.28 billion |
| Federal Perkins Loans | \$0 (CR p. 1319) | \$300 million | \$0 (CR p. 1319) | \$0 (Ed.J.) | \$300 million |

| DEPARTMENT AGENCY PROGRAMS | FY10 PRESIDENT'S REQUEST | FY10 COALITION'S REQUEST | FY10 OMNIBUS | FY11 PRESIDENT'S REQUEST | FY11 COALITION REQUESTS |
|--|----------------------------|--------------------------|----------------------------|---------------------------|---|
| Federal Family Education Loans (credit activity). Legislative Proposal on Mandatory Outlays | \$1.166 billion | N/A | \$0 | \$0 (Ed.J. p. C-3) | \$0 |
| Academic Competitiveness Grants/SMART Grants | \$1.386 billion | \$1.2 billion | \$0 | \$0 (Ed.J. p. C-3) | \$1.2 billion |
| GEAR UP | \$313 million (CR p. 1321) | \$400 million | \$323 million (CR p. 1321) | \$323 million (PB p. 377) | \$400 million |
| Thurgood Marshall Legal Education Opportunity Program | \$3 million (CR p. 1322) | \$5 million | \$3 million (CR p. 1322) | \$3 million (PB p. 377) | \$5 million |
| DEPARTMENT OF EDUCATION AID FOR INSTITUTIONAL DEVELOPMENT/PROGRAM DEVELOPMENT | | | | | |
| Strengthening Institutions Title III, Part A | \$64 million (CR p. 1320) | \$126.3 million | \$64 million (CR p. 1320) | \$68 million (PB p. 376) | \$88 million |
| Strengthening Historically Black Colleges Title III, Part B, Section 323 Discretionary Funding Mandatory Funding | \$250 million (CR p. 1320) | \$1 billion | \$267 million (CR p. 1320) | \$280 million (PB p. 376) | \$292 million \$850 million (SAFRA)* |

* \$850 million in mandatory funding over ten years for Strengthening HBCUs was included in the Health and Education Budget Reconciliation package.

| DEPARTMENT AGENCY PROGRAMS | FY10 PRESIDENT'S REQUEST | FY10 COALITION'S REQUEST | FY10 OMNIBUS | FY11 PRESIDENT'S REQUEST | FY11 COALITION REQUESTS |
|--|------------------------------|--------------------------|------------------------------|-------------------------------|-------------------------|
| Title III, Part B, Section 326 | \$61.4 million (CR p. 1320) | \$100 million | \$61.4 million (CR p. 1320) | \$65 million (PB p. 376) | \$65 million |
| Title III, Part C, Endowment Grant | \$0 | \$25 million | \$0 | \$0 | TBD |
| HBCU Capital Financing | \$20.58 million (CR p. 1323) | \$15.354 million | \$20.58 million (CR p. 1323) | \$20.58 million (PB p. 379) | \$21 million |
| Minority Science and Engineering Improvement Program (MSEIP) | \$9 million (CR p. 1321) | \$20 million | \$9.5 million (CR p. 1321) | \$9 million (PB p. 376) | \$20 million |
| Title VI, Institute for International Public Policy (IIPP) | \$1.84 million (CR p. 1321) | \$3.2 million | \$1.95 million (CR p. 1321) | N/A | TBD |
| Title VII, Masters / degree programs at HBCUs and PBIs | \$11 million | \$15 million | \$11.5 million | \$11.5 million | \$15 million |
| Title VI, International Education (domestic/overseas) | \$119 million (CR p. 1321) | N/A | \$125.9 million (CR p. 1321) | \$126 million (PB p. 376) | TBD |
| DEPARTMENT OF EDUCATION OTHER | | | | | |
| Title II, Teacher Quality Enhancement Grants | \$50 million (CR p. 1322) | \$150 million | \$43 million (CR p. 1322) | \$405 million (Ec.J. p. F-14) | \$50 million |

| DEPARTMENT AGENCY PROGRAMS | FY10 PRESIDENT'S REQUEST | FY10 COALITION'S REQUEST | FY10 OMNIBUS | FY11 PRESIDENT'S REQUEST | FY11 COALITION REQUESTS |
|---|--------------------------------|-----------------------------|---------------------------------|----------------------------------|----------------------------|
| Howard University | \$235 million (CR p. 1323) | N/A | \$235 million (CR p. 1323) | \$235 million (PB p. 378) | TBD |
| OTHER DEPARTMENTS AND AGENCIES DEPARTMENT OF HEALTH & HUMAN SERVICES | | | | | |
| Health Professionals for Diversity/HRSA | \$100 million (CR p. 1267) | \$117,686 million | \$97.3 million (CR p. 1267) | \$97.3 million | TBD |
| Minority Centers of Excellence | \$24.6 million (CR p. 1267) | \$33.6 million | \$24.6 million (CR p. 1267) | \$24.6 million (HHS.J. p. 28) | TBD |
| Health Careers Opportunity Program | \$22.1 million (CR p. 1267) | \$35.65 million | \$22.1 million (CR p. 1267) | \$22.1 million (HHS.J. p. 28) | TBD |
| Scholarships for Disadvantaged Students | \$52.8 million (CR p. 1267) | \$47.13 million | \$49.34 million (CR p. 1267) | \$49.3 (HHS.J. p. 28) | TBD |
| Faculty Loan Repayment | \$1.2 million (CR p. 1267) | \$1.3 million | \$1.27 million (CR p. 1267) | \$1.27 million (HHS.J. p. 83) | TBD |
| NIH National Center on Minority Health Disparities | \$209 million (CR p. 1282) | \$250 million | \$211.6 million (CR p. 1282) | \$219 million (PB p. 477) | TBD |
| NIH Research Centers at Minority Institutions | \$56 million (CR p. 1300) | \$75 million | \$56 million (CR p. 1300) | N/A | TBD |

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Public Witness Testimony for the Record

Organized labor has many responsibilities. One of those is ensuring that contractual agreements are complied with by the company. This doesn't always include health and safety. Unions rely heavily on the Occupational Safety and Health Administration (OSHA) and its standards; however, there is a need to go beyond these requirements. The Voluntary Protection Programs (VPP) allows for further growth by requiring Union participation.

The VPP program isn't just another government program. VPP sites must meet and are expected to exceed current OSHA regulations, enhancing worker safety and health. The program does not only target compliance issues; it takes a close look at already existing safety programs, making recommendations for enhancement and improvement. VPP requires meaningful employee involvement and employees often have a more critical eye regarding the actual hazards to which they are exposed on a daily basis.

Participation in the VPP process empowers Unions in the safety arena and enables opportunities for training for represented employees. When Unions work with OSHA in the VPP process, Union members are involved in developing, instituting and sustaining safety programs and policies.

For years, Unions utilized the resources available to them, which were limited and costly. There still remained a delay and reluctance on a company's part to adopt Union recommendations. If a company was compliant with OSHA standards, they did not see a need to go further. As VPP participants, we have always believed in going beyond mere compliance, because there are still incidents of worker injury and illness. Prior to VPP, ideas for safety improvement from workers may have fallen on deaf ears at times. Through VPP however, there are processes in place for these ideas to be discussed and in most cases implemented when justified, making work areas much safer for all employees. This process also allows employees to take ownership of the safety and health programs and gives them a stake in the success of VPP and their safety and health programs at their worksites.

Because some of the OSHA standards are outdated and have not kept up with technology, workplaces that are compliant can still have hazards and not fully protect the workers at the site. VPP sites focus on the hazard, regulated or unregulated and are expected to work cooperatively with their partners to address all hazards. They not only follow all OSHA regulations, but are expected to exceed them. A good example is the area of ergonomics. Although there is currently no OSHA ergonomic standard, VPP requires participating sites to address ergonomic issues.

At VPP sites, management leadership is a requirement and management takes a more proactive role to work toward better safety and health programs. There are avenues in place for hazards to be identified and for hourly worker and Union leadership concerns to be heard. VPP companies are more responsive to fixing the problems that arise.

Management at VPP sites must be willing to commit the resources necessary to alleviate hazards.

Many Unions struggle with uncontrolled hazards in the workplace due to a lack of adequate safety and health training. One of the reasons Unions make such a difference is that they ensure that their safety and health representatives are trained. VPP requires safety and health training for all employees, Union and management, to identify and control or eliminate workplace hazards. It also is common for VPP sites to have Union members who work full time in safety and health positions.

Over the past 15 years, efforts have been made in nearly every state to “reform” workers’ compensation. There are certainly many areas of the system that need reform. At least some of the current efforts in reforms have weakened workers’ protections and rights. Among commonly sought changes in the laws are (a) limiting the time workers can receive benefits (b) a reclassification of injuries as “non occupational”; (c) limiting the workers’ right to choose their own doctors instead of the employer’s doctor; and (d) some apparent use of inappropriate medical guidelines to decide whether and how much a worker is disabled. The best way to reduce workers’ compensation costs is to prevent injuries and illnesses at work. This can be done through effective health and safety programs that VPP requires that give workers and their Union representatives a meaningful role in the process and through.

If companies and its Unions are to secure safety and health together for American workers, we will need the continuing commitment of all parties, including OSHA, to move forward. As part of the path forward, OSHA’s most successful safety and health program must be funded and allowed to grow. VPP sites typically have 50% fewer workplace injuries than non VPP like sites. VPP sites also provide a model to and outreach for other sites to raise their programs up to meet or exceed the OSHA standards and protect American workers.

Increasing OSHA compliance staffing on OSHA staffing will help have a positive impact on safety and health in this country, but can not be the only tool. In a report issued in March 2005, the Government Accountability Office (GAO) noted that since OSHA can only inspect a small fraction of the Nations workplaces each year, voluntary strategies may provide important opportunities to extend the Agency’s influence. GAO concluded that OSHA’s voluntary compliance strategy shows promising results.”²

VPP requires having an initial onsite evaluation followed by re-approvals every three to five years. Also, VPP requires that a site conduct an annual, self evaluation for all the aspects of the site safety and health management system. This audit must be sent to the OSHA VPP manager, to assure that the company is complying with the process. Safety and health legislation takes time and changes can become bottlenecked in the political system. Workers need to be given a real voice in the workplace and real rights to participate in health and safety as part of a comprehensive safety program to identify and correct hazards. VPP requires this as part of the initial application submitted. VPP has an expectation set forth in the Policies and Procedures Manual that requires equal opportunity to achieve and go beyond safety and health standards.

VPP sites support the use of compliance when needed and help OSHA to free up OSHA resources. Through the use of the Special Government Employee (SGE) program,

² 2004 GAO Report (GAO-04-378 March 19, 2004) Titled Workplace Safety and Health: OSHA Voluntary Compliance Strategies Show Promising results, but Should be Evaluated Before They are Expanded.

OSHA resources are freed up to address compliance issues. The SGE program allows Union members to be trained and work with OSHA as a team members on VPP site inspections. The SGE program also allows Union team members the ability to view best safety and health practices at other sites and bring that knowledge back to improve safety and health at their own site.

VPP sites have more effective contractor management. VPP sites are usually stricter on contractor safety and health and manage their contractors accordingly. This provides a safer working environment for the Union floor employee and raises the safety and health expectations of the contractor employee.

By entering into the VPP process, doors are opened to improve safety and health at Union sites through networking and cooperative efforts between the Unions, the companies and OSHA. Networking allows Unions at VPP sites to help improve safety for Union brothers and sisters at other sites. Site should go beyond compliance to take advantage of opportunities available through OSHA's VPP program to improve safety and health across the country.

Workplace expectations should be developed as a joint venture, including safety and health programs, policies and procedures to promote VPP in a labor organization, involve them in the process and provide a forum for them to voice their concerns. Understanding the importance and requirement of employee involvement in VPP and the process for resolving safety and health issues under the VPP requirements is key to achieving safety and health success. The VPP process implements long term safety and health continuous improvement for Union work sites that effectively protect workers.

OSHA's other cooperative programs. Most of these alliances are between OSHA and employer groups with no requirements for Union participation. VPP goes beyond this by requiring that the Unions are involved in the process and support the VPP program from the start. Union safety and health committees have produced letters of declaration on worker involvement that state that "trade Union safety representatives, through their empowered role for purposes of consultation, often lead to higher levels of compliance and better health and safety performance than in non-trade Union systems."¹

Union employees give up none of their OSHA Act rights. All employee rights under the OSH Act are retained and in some ways enhanced. It is possible; due to resource issues OSHA could inspect workplaces under its jurisdiction once every 97 years. The VPP program requires having an initial onsite evaluation followed by re-approvals that occur every 3 to 5 years. Union members have people they can call for help at OSHA that they have developed relationship with and get answers and solutions to their questions. OSHA feels like a partner in improving safety at their site.

A VPP site is expected to meet or exceed all OSHA safety and health standards. Union members still retains their right to a file complaint with OSHA. OSHA will still investigate and the company must send back documentation of how the issue has been resolved to OSHA's satisfaction. VPP sites are OSHA's best safety and health sites and OSHA has put its reputation on the line. OSHA takes complaints at VPP sites very seriously and holds the company accountable. If there are multiple injuries or a fatality OSHA would still perform a compliance audit and hold the site responsible.

At this time, the federal government has placed great emphasis on the expansion of OSHA's enforcement program. A focus on enforcement is definitely needed, but not at

¹ Health Safety Executive Commission/ Peter Kirby/HSE/ Trade Union Trends 2003

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the expense of OSHA's VPP programs. VPP must be funded. OSHA's VPP program impacts almost one million American workers directly and countless others through the mentoring and outreach performed by OSHA's VPP sites. To move forward in protecting America's workers, VPP is needed to provide leadership with all its partners, labor, management and OSHA, that can impact and improve safety and health for all American workers.

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UNITED TRIBES TECHNICAL COLLEGE

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FY 2011 Department of Education Appropriations: Carl Perkins Act (Section 117);
Higher Education Act Title III; and TRIO Programs

Submitted to
House and Senate Appropriations Subcommittees on Labor-HHS-Education and Related Agencies

David M. Gipp, President, United Tribes Technical College
Myra Pearson, UTTC Board Chairman and Chairman of the Spirit Lake Tribe

April 9, 2010

For 41 years, United Tribes Technical College (UTTC) has provided postsecondary career and technical education, job training and family services to some of the most impoverished Indian students from throughout the nation. Unemployment among the Great Plains tribes, where most of our students are from, typically run at about 75 percent. We are governed by the five tribes located wholly or in part in North Dakota; we are not part of the North Dakota state college system and do not have a tax base or state-appropriated funds on which to rely. We have consistently had excellent retention and placement rates and are a fully accredited institution. Section 117 Perkins funds represent about half of our operating budget and provide for our core instructional programs. The request of the United Tribes Technical College Board is for the following authorized programs:

- *\$10 million for base funding authorized under Section 117 of the Carl Perkins Act (20 U.S.C. Section 2327).* This is \$1.8 million above the FY 2010 level. These funds are shared via a formula by United Tribes Technical College and Navajo Technical College.
- *\$36 million as requested by the American Indian Higher Education Consortium for Title III (Section 316) of the Higher Education Act (Strengthening Institutions program) that provides construction funds for facilities at tribally controlled colleges.* This is \$4 million over the FY 2010 level. Among UTTC's pressing facility needs is funding for phase II of our science and technology building and for student housing. We are working to cobble together various sources of funding to complete the science and technology building and to build student housing..
- *\$973 million for the TRIO programs nationally* which is \$120 million over the requested amount. This would replace the \$57 million in mandatory funding that is expiring for the Upward Bound program plus provide an increase for other TRIO programs.

Base Funding. Funds requested under Section 117 of the Perkins Act above the FY 2010 level are needed to: 1) maintain 100-year-old education buildings and 50 year old housing stock for students; 2) upgrade technology capabilities; 3) provide adequate salaries for faculty and staff (who have not received a cost of living increase this year and who are in the bottom quartile of salary for comparable positions elsewhere); and 4) fund program and curriculum improvements, including at least three four-year degree programs.

Acquisition of additional base funding is critical as UTTC has more than tripled its number of students within the past six years but actual base funding for educational services has increased only 25 percent in that period. Our Perkins funding provides a base level of support allowing the college to compete for discretionary contracts and grants leading to additional resources annually for the college's programs and support services.

Title III (Section 316) Strengthening Institutions. We need Title III construction funds for:

Science and Technology Building. UTTC provides education for more than 1,000 students in 100-year old former military buildings (Fort Abraham Lincoln), along with one 33-year old "skills center" which is inadequate for modern technology and science instruction. We have completed Phase I of the building and now look to complete Phase Two. We have raised \$5 million, including \$1 million in private funding, \$3 million from the U.S. Department of Education and \$1 million in borrowed funds. The total project cost is expected to be around \$12 million. Our current facility lacks laboratories with proper ventilation and other technologies which are standard in science education. We lack a modern auditorium/lecture hall with features such as computer internet access and electrical outlets and a library with appropriate computer stations. Our present library has been cited by the accrediting agency as being inadequate.

Student Housing. We are constantly in need of more student housing, including family housing. We would like to educate more students but lack of housing has at times limited the admission of new students. With the expected completion of a new Science and Math building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families. New housing on the South Campus could also accommodate those persons we expect to enroll in a new police training programs.

While UTTC has constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of the old Fort Abraham Lincoln, as well as in duplexes and single family dwellings that were donated to UTTC by the federal government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings for housing are actually cheaper than trying to rehabilitate the old buildings that now house students.

TRIO Programs. United Tribes Technical College currently has no TRIO funding. We are in particular need of funding from the student Support Services Program to improve retention, transfer, and graduation rates for our Pell Grant recipients. Our students need tutoring, mentoring, academic counseling and career development services to help them successfully complete their academic courses of study. Our study body meets the eligibility requirements of TRIO's Student Support Services program.

- 83 percent of students meet the low-income criteria for TRIO's Student Support Services
- 68 percent of our students are first generation college attendees
- 17 percent of all UTTC applicants in 2008 had a Graduate Equivalency Diploma
- 74 percent of our students need remediation in math, reading and composition
- 80 percent of our students have Limited English proficiency

With regard to our students with a Limited English background, we note that although not all UTTC students speak their Native language fluently, many speak forms of English that differ from Standard English because of the influence of other languages' vocabulary, intonation, and vernacular. Although UTTC strongly supports the preservation and use of Native languages, our students tend to have difficulty reading, writing, and speaking the Standard English as is required of them by the College and the workplace.

We also note the January 13, 2009, report of the Department of Education's Office of Vocational and Adult Education on its recent site visit to UTTC (October 7-9, 2008). While some suggestions for improvements were made, the Department commended UTTC in many areas: for efforts to improve student retention; the commitment to data-driven decision-making, including the implementation of the Jenzabar system throughout the institution; the breadth of course offerings; collaboration with four-year institutions; expansion of online degree programs; unqualified opinions on both financial statements and compliance in all major programs; being qualified as a low risk grantee; having no reportable conditions and no known questioned costs; clean audits; and use of the proposed measurement definitions in establishing institutional performance goals.

Below are some important things we would like you to know about our College:

UTTC Performance Indicators. United Tribes Technical College has:

- An 85 percent retention rate.
- A placement rate of 94 percent (job placement and going on to four-year institutions).
- A projected return on Federal investment of 20-to-1 (2005 study comparing the projected earnings generated over a 28-year period of UTTC Associate of Applied Science and Bachelor degree graduates of June 2005 with the cost of educating them).
- The highest level of accreditation. The North Central Association of Colleges and Schools has accredited UTTC again in 2001 for the longest period of time allowable – ten years or until 2011- and with no stipulations. We are also one of only two tribal colleges accredited to offer accredited on-line (Internet based) associate degrees.
- More than 20 percent of graduates go on to four-year or advanced degree institutions.

Our students. Our students are from Indian reservations throughout the nation, with a significant portion of them being from the Great Plains area. Our students have had to make a real effort to attend college; they come from impoverished backgrounds or broken families. They may be overcoming extremely difficult personal circumstances as single parents. They often lack the resources, both culturally and financially, to go to other mainstream institutions. Through a variety of sources, including Perkins funds, UTTC provides a set of family and culturally-based campus services, including: an elementary school for the children of students, housing, day care, a health clinic, a wellness center, several on-campus job programs, student government, counseling, services relating to drug and alcohol abuse and job placement programs. We are currently serving 168 students in our elementary school and 169 youngsters in our child development centers.

UTTC course offerings and partnerships with other educational institutions. We offer accredited vocational/technical programs that lead to 17 two-year degrees (Associate of Applied Science and eleven one-year certificates, as well as a four-year degree in elementary education in cooperation with Sinte Gleska University in South Dakota. We intend to expand our 4-year degree programs. While full information may be found on our web site (www.uttc.edu), among our course offerings are:

Licensed Practical Nursing. This program results in great demand for our graduates; students are able to transfer their UTTC credits to the North Dakota higher educational system to pursue a four-year nursing degree.

Medical Transcription and Coding Certificate Program. This program provides training in transcribing medical records into properly coded digital documents. It is offered through the college's Exact Med Training program and is supported by Department of Labor funds.

Tribal Environmental Science. This program is supported by a National Science Foundation Tribal College and Universities Program grant. This five-year project allows students to obtain a two-year AAS degree in Tribal Environmental Science.

Community Health/Injury Prevention/Public Health. Through our Community Health/Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the U.S. population. This program has in the past been supported by the IHS, and is the only degree-granting Injury Prevention program in the nation. Given the overwhelming health needs of Native Americans, we continue to seek resources for training of public health professionals.

Online Education. Our online education courses provide increased opportunities for education by providing web-based courses to American Indians at remote sites as well as to students on our campus. These courses provide needed scheduling flexibility, especially for students with young children. They allow students to access quality, tribally-focused education without leaving home or present employment. We offer online fully accredited degree programs in the areas of Early Childhood Education, Community Health/Injury Prevention, Health Information Technology, Nutrition and Food Service and Elementary Education.

Criminal Justice. Our criminal justice program leads many students to a career in law enforcement, and as noted elsewhere in this testimony, we are actively working on establishing a police training academy at UTTC.

Computer Information Technology. This program is at maximum student capacity because of limitations on resources for computer instruction. In order to keep up with student demand and the latest technology, we need more classrooms, equipment and instructors. We provide all of the Microsoft Systems certifications that translate into higher income earning potential for graduates.

Nutrition and Food Services. We help meet the challenge of fighting diabetes and other health problems in Indian Country through education and research. As a 1994 Tribal Land Grant institution, we offer a Nutrition and Food Services AAS degree in order to increase the number of Indians with expertise in nutrition and dietetics. There are few Indian professionals in the country with training in these areas. We have also established a Diabetes Education Center that assists local tribal communities, our students and staff to decrease the prevalence of diabetes by providing food guides, educational programs, training and materials.

Our Perkins and Bureau of Indian Education funds provide for nearly all of our core postsecondary educational programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time supplemental funds which help us provide the services our students need to be successful. We cannot continue operating without Perkins funds.

Thank you for your consideration of our requests.

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Written Testimony of
R. Davis Layne
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For the Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
2358-C Rayburn House Office Building
Washington, D.C. 20515

May 19, 2010

On behalf of the Voluntary Protection Programs Participants' Association, Inc. (VPPPA), I would like to address the importance of providing direct federal funding in the Fiscal Year 2011 budget for the Occupational Safety and Health Administration's (OSHA) Voluntary Protection Programs (VPP).

Safety and health in the workplace requires the careful balance of both enforcement methods and cooperative programs. VPP has proven to be one of OSHA's premier programs, adding value to workplace safety and health by encouraging worksites to go beyond mere compliance. The success of VPP is based on its dynamic approach encouraging safety and health beyond targeted goals of traditional enforcement. VPP encourages a cooperative relationship among management, labor and government, promoting worker protection, requiring active employee involvement, management commitment and union support.

Despite VPP's successes and a \$10 million increase for enforcement in the President's FY 2011 budget, Labor Secretary Hilda L. Solis announced that she will decrease funding for compliance assistance by over 3 million, cutting financial support for VPP. In addition, Solis has stated her plans to re-direct resources, such as 35 Compliance Safety and Health Officers, from cooperative programs to work directly on enforcement activities.

VPP sites support OSHA's firm and fair enforcement. However, as the science of safety and health has matured, there is clear evidence that 40 years of OSHA enforcement have not produced the cultural change required in industry today to keep American workers safe and American companies competitive in a global marketplace. While enforcement only addresses one of the objectives of the OSH Act, VPP was established on the foundation of three of the 13 mandates. These requirements are directly related to the development of cooperation between employer and employee to establish a safe workplace. We cannot regress and think more enforcement will produce different outcomes. VPP is the only progressive and comprehensive safety and health management system in OSHA's tool box that achieves measurable and sustainable improvements in the protection of the American workforce.

Unlike enforcement, VPP is a safety and health management system that addresses real problems in real time, leading the way for more current safety and health program standards. For instance, VPP addresses ergonomics as a recognized hazard in the workplace and also fulfills the requirements of recordkeeping as focused upon in OSHA's current National Emphasis Program. Furthermore, acting as a force-multiplier, VPP frees up resources for OSHA as VPP site representatives become ambassadors for safety and health excellence, engaging in outreach and training so that other sites can improve their safety and health as well.

The successful implementation of the Special Government Employee (SGE) program for VPP exemplifies the commitment to safety and health by VPP worksites. Corporations support employees in becoming SGEs and assisting OSHA personnel during VPP onsite evaluations. Not only does the SGE program supplement OSHA resources in performing onsite evaluations, this innovative program gives industry, government and labor an opportunity to work together to enhance workforce protection across the nation.

Ironically, at the same time the agency is pushing enforcement, OSHA has also begun looking at employers who are using injury and illness prevention programs in search of comprehensive safety and health management systems that have management and employees working together towards continuous improvement. Assistant Secretary of Labor Dr. David Michaels stated during a meeting of Maritime Advisory Committee meeting in January 2010, "We expect employers to assess problems that are out there and try to fix them. We don't like this system where its sort of catch me if you can. We expect you to take care of that. So we're thinking about ways to encourage employers to essentially have a program."

The ideal injury and illness prevention program that OSHA continually describes is VPP. VPP improves communication within the worksite, positively affecting relationships between the workers and managers and resulting in better productivity. The program emphasizes continual identification and elimination of hazards as worksites strive to excel in workplace safety and health. Furthermore, VPP offers an opportunity for American companies to be more competitive through the reduction of workers' compensation costs, thereby potentially keeping more jobs in America, increasing the competitiveness of small businesses, while more importantly, protecting the lives of our nation's workforce.

On April 26, 2007, in a statement to the subcommittee on employment and workplace safety, U.S. Senate Committee on Health, Education, Labor & Pensions, Dr. Michaels, himself, stated: "OSHA enforcement does not appear to be effective in further reducing injury rates." He continued, "In all of its voluntary programs, like the Voluntary Protection Programs (VPP) and its 'alliances,' OSHA emphasizes the importance of employers providing a safe workplace, not merely meeting the specific requirements on all of OSHA's rules. This is as it should be, and, more than anything else, this is the message that should go to all employers."

Despite the evidence, OSHA has no plans to directly fund VPP. In a report to the House Budget Committee on March 4, 2010, Congressman George Miller (D-CA), chair of the House Committee on Education and Labor, also supported the shift of funding and resources away from VPP in favor of enforcement. He proposed to fund VPP "*through a user fee, and plans to work on establishing authority for augmenting the OSHA budget through a fee based system.*"

The members of the Voluntary Protection Programs Participants' Association, Inc. (VPPPA) have expressed opposition to a user fee system for certification. Some repeated concerns include:

- Industry directly funding the government to perform part of its required function under the OSH Act.
- Creating the perception that employers are "buying" the VPP flag.
- Creating a situation where employers can be perceived as purchasing "an exemption from routine OSHA inspections."
- Fees for VPP deterring small businesses from participating.
- Charging sites for participation in VPP despite of what VPP sites voluntarily give in the form of mentoring, outreach, assist visits, funding Special Government Employees for onsite evaluations and providing education and training opportunities via regional and national conferences.

- Paying a fee would eliminate the independent verification of a site's safety and health management system and reduce VPP to a government recognition program, rather than the valuable workplace safety culture change-agent and source of worker pride.

Unlike many fee-based certification programs, VPP is a comprehensive workplace safety and health management system that is built on cooperation among workers, employers and government. We cannot let the Department of Labor (DOL) back away from the partnership in VPP nor diminish the program by establishing a user fee for collaboratively working to go beyond OSHA's outdated standards.

Secretary Solis's goals for 2010, which include to "secure safe and healthy workplaces, particularly in high-risk industries," to "assure fair and high quality work-life environments," and to "ensure worker voice in the workplace," are all elements of VPP. Driven by workers, the ideals of continuous improvement and partnerships among management, labor and government are fundamental to the success of VPP. Worksites from the 270 industries involved in VPP are 54% below the Bureau of Labor Statistics (BLS) Total Recordable Cases of Injuries and Illnesses rate and 51% below the BLS, Days Away from Work, Restricted Work Activity, or Job Transfer rate. VPP coupled with enforcement provides the proper balance to achieve the safest and healthiest American workforce.

As President Obama said very clearly during his remarks on the economy on January 28, 2009, "...what makes an idea sound is not whether it's Democratic or Republican, but whether it makes good economic sense for their workers and companies." Restoring direct funding for OSHA's VPP will enable the agency to better meet the Department's outcome goals to secure safe and healthy workplaces and enhance workers' voice in the workplace.

**Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
House Committee on Appropriations
2358-C Rayburn House Office Building
Washington, D.C. 20515**

Friday, April 16, 2010

**Attention: Fiscal Year 2011 Public Witness Record
Contact: Cindy Hounsell, President, WISER**

On behalf of the Women's Institute for a Secure Retirement (WISER), we are writing to submit written testimony for the Fiscal Year 2011 Public Witness Record.

We are submitting this testimony to ensure that Committee members recognize the significant financial risks women face in our volatile economy. While all of us feel the struggle of today's economic crisis in some way, it is especially troubling for older women, many of whom are already living on the edge. As the aging population is rapidly increasing, longevity risks have a disproportionate impact on women who need more retirement income as they experience more frailty and chronic illness and are less likely to have a spouse as a caregiver. By age 75, many women are living in poverty for the first time in their lives. To change the course of women's lives, women and their families are in need of better tools and information in their communities to determine how to make their money last for their lifetime and to know how to protect assets from predatory practices.

Introduction

The Women's Institute for a Secure Retirement (WISER) is a non-profit organization whose primary mission is to improve the long-term financial security of all women through education and advocacy. WISER provides women with the crucial skills and information they need to become financially capable and improve their economic circumstances. As the only organization to focus exclusively on the unique financial challenges that women face, WISER supports women's opportunities to secure adequate retirement income through its training workshops, education materials, outreach and research. WISER operates the National Education and Resource Center on Women and Retirement Planning, (the Center) with the U.S. Administration on Aging.

Increasing Funding

The Center is efficient and effective, fills a niche that is not filled by anyone else and our reach and impact are increasing. We have made an impact in nearly 40 states and our evaluations are always positive. While we accomplish a lot with minimum funding an increase to \$1 million would expand the capacity of the Aging Services Network by reaching high risk seniors and

underserved populations with critical financial information and help older women make better financial decisions in order to avoid financial exploitation, the risk of becoming destitute and overly dependent on government programs.

Background

The Center addresses the underlying causes of women's lack of retirement income and helps them to measure and improve their individual Retirement Readiness, (a WISER initiative), in order to make the best decisions and retire in dignity rather than in need. Lack of knowledge of future planning places women at a significant risk. Experience and research shows that relevant financial information can dramatically increase total net worth by nearly one-third for those with the lowest income and eighteen percent for those with moderate income. One in four older women lives in poverty. Women become poorer as they age and many are poor for the first time in their lives in old age. Minority women are the poorest – nearly 40 percent of single Black and Hispanic women live in poverty. A woman's biggest risk is outliving assets. Half of all retired women receive less than \$61 a month in asset income. The population of age 80+ women is expected to double and the number of older women needing services is rapidly increasing.

Need and Use of Funding:

Few programs offer successful interventions to low-wage workers or minority women. WISER initiatives include an intervention for the Aging Network that provides financial planning information, comprehensive and user-friendly retirement resources available through the internet clearinghouse and five model programs that are accessible to the Family Caregiver Support Programs, the Area Agencies on Aging, the Aging and Disability Resource Centers, the Alzheimer's Demonstration Program, Adult Protective Services and the Pension Counseling Programs.

The project provides technical and financial support to partners, who integrate retirement planning issues into the agenda of community groups. Costs include the funding for the partners who will extend and assist outreach by training-trainers and aiding collaboration. Using the latest technology, WISER offers the materials, train-the-trainer sessions and teaching manuals to make the program available nationwide. Research and evaluations show that the right interventions strengthen the capacity of all women to plan for their economic security and long-term care needs. The ever-increasing pressures on the Medicaid system, particularly for long-term care, are a sad testimony to the lack of personal resources and choices many individuals face in retirement. Being financially prepared helps women live with more financial security, and empowers them to have choices in the long-term care arena, such as either home or community based care.

After a lifetime of caring for others, women face a host of obstacles that jeopardize their economic security in retirement. Women live longer than men do. They earn less for the same work. Caregiving responsibilities cause them to spend about nine years out of the job market. Fewer years at work means that they are less likely to be eligible for employer retirement benefits and, combined with lower pay, means smaller Social Security benefits and lower

savings. Older women are much more likely to live alone than older men, which increases the likelihood of poverty.

Divorce is especially pernicious for women's financial security in retirement. Most women (and many lawyers) fail to take the appropriate action during the divorce proceedings to secure their rights to retirement benefits. What's more, women who are married less than 10 years are not eligible for spousal Social Security benefits. The average length of a first marriage is eight years. Even older women who seem to be financially secure are at risk. Elder financial abuse is a growth industry and predatory lending costs Americans billions annually. It robs elderly women of precious assets and puts their home ownership at risk. A Consumers Union study found that subprime loans are concentrated in geographical areas with higher concentrations of elderly residents. A high concentration of older adults predicts a higher rate of predatory lending. The face of the victim is often a "cash poor, house rich" elderly widow.

Here are some eye-opening facts:

- In 2008, women working full-time earned a median salary of \$35,308, compared to \$44,668 for men. The disparity is even more dramatic for minority women: \$27,535 for black women and \$22,285 for Hispanic women. When women who work part-time are included, the median income for all working women drops to \$29,074. Lower income during working years leads to lower income and the future threat of poverty.
- Only 29% of women over age 65 receive income from pensions or annuities compared to 43% of men.
- The average Social Security benefit for retired women workers in 2008 was \$948 a month compared to \$1,235 received by men.
- Women represent 70% of the older population living in poverty.

The Story Stays the Same

For more than a decade, hundreds of thousands of women in their 60's have been forced to stay in the workforce because they lack sufficient money to retire. We have heard from and about women in their 60s, 70s, and even 80s who struggle to survive on Social Security benefits alone. They've lost jobs, had to quit working for health reasons, or made the mistake of retiring too early. We know of women who have lived out of their cars – women who once had good-paying and steady jobs. The financial tightrope older women must walk often drops them into poverty. In fact, one in five women over age 65 live in poverty today.

How the Center's Program Operates to Help With Financial Decision-Making

The do-it-yourself nature of retirement preparation has left millions of workers to make complex decisions. These aren't just retirement planning decisions; they are life-defining decisions, and most people aren't prepared to make them. This puts women in the difficult position of making big decisions while being unable to afford even a small mistake.

WISER's approach is to bring financial planning back to the basics. Our goal is to help women make the best decisions they can with the limited resources they may have and to avoid exploitation and victimization. We educate them on the risks of longevity, inflation, and lifestyle changes. We train trainers who assist women in their communities. We explain the hard reality of having to adjust living standards to live within their means and to find help and resources that they may not be aware of.

Before the economic crisis, the women we reached were often confounded and intimidated. If they were following any advice, it may have been from a co-worker, neighbor or a family member—not the best basis for making life-defining decisions. Now many women are in a state of panic. They want someone to help guide them to make the best choices.

The Center has directly reached tens of thousands of women through our workshops, our partners' workshops and millions more with our publications and website. WISER's strength is providing women with core financial knowledge that encourages them to make financial and retirement planning a priority in their lives. We focus on such issues as health and retirement benefits at work (or the implication of the lack of such benefits), the financial implications of providing care for children, parents and spouses, and the risks of longevity.

This initiative began in 1998, and now includes many partners—employers, aging and women's organizations and community-based groups. We have also worked with other federal agencies, including the Department of Agriculture's Cooperative Extension Service, the Department of Labor, and the Social Security Administration.

Our core message is this: women face unique challenges that threaten their financial security in retirement. As Congress and the Administration look to find ways to address the impact of the current economic crisis and to on older workers, please keep in mind the unique situation of women.



STATEMENT OF MATTHEW E. MELMED
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**FOR THE HOUSE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION COMMITTEE ON APPROPRIATIONS**

Thank you for the opportunity to provide testimony to the Subcommittee regarding the critical need to invest in programs that support the healthy development of children during the first three years of life. My name is Matthew Melmed. For the last 14 years I have been the Executive Director of ZERO TO THREE. ZERO TO THREE is a national non-profit organization that has worked to advance the healthy development of America's babies and toddlers for over thirty years. I would like to start by thanking the Subcommittee for all of its work to ensure that our nation's at-risk infants and toddlers have access to early intervention and positive early learning experiences.

We know from the science of early childhood development that infancy and toddlerhood are times of intense intellectual engagement.¹ During this time – a remarkable 36 months – the brain undergoes its most dramatic development, and children acquire the ability to think, speak, learn, and reason. All babies and toddlers need positive early learning experiences to foster their intellectual, social, and emotional development and to lay the foundation for later school success. Babies and toddlers living in high-risk environments need additional supports to promote their healthy growth and development. Disparities in children's cognitive and social abilities become evident well before they enter Head Start or Pre-Kindergarten programs at age four.

We also know that investing in programs that promote positive early experiences not only benefits individual infants and toddlers, but also benefits society in ways that exceed program costs. The work of economist and Nobel laureate James Heckman has shown that the rate of return on human capital investment is greatest in programs targeted towards the earliest years.² Supporting early interventions for at-risk babies and toddlers promotes school retention, improves the quality of the workforce, raises earnings, strengthens social attachments, and reduces crime, teenage pregnancy, and welfare dependency.³ In short, helping children get a good start in life—as opposed to making them play catch up when they reach school and beyond—is sound business sense as well as social sense.

I want to focus on why it is important to increase funding for three programs critical to meeting the unique needs of low-income infants and toddlers – Early Head Start (EHS), the Child Care and Development Fund (CCDF) and Part C of the Individuals with Disabilities Education Act (IDEA).

Early Head Start: Increase Head Start Funding by \$989 million to Continue Serving At-Risk Babies and Toddlers.

Early Head Start is the only federal program specifically designed to ensure that all young children have the same opportunities by improving the early learning experiences of low-income infants and toddlers. Research shows that EHS puts at-risk infants and toddlers on the right path to school readiness. The Congressionally-mandated Early Head Start Research and Evaluation Project, a rigorous, large-scale, randomized control study, found that children who participate in the program had significantly larger vocabularies and scored higher on standardized measures of cognitive development than did children in a control group. EHS children and parents had more positive interactions, and these parents provided more support for learning than did those in a control group.⁴ In addition, a follow-up wave of research found that a number of positive impacts were still demonstrated two years later. Moreover, when the effects of EHS in combination with pre-kindergarten education were examined, children who attended EHS and formal child development programs between the ages of 3 and 5 experienced the most positive outcomes.⁵

Prior to the American Recovery and Reinvestment Act (ARRA), EHS served less than three percent of eligible infants and toddlers. Funding designated for EHS in ARRA gave a much-needed boost to the program, enabling it to expand services to 50,000 more children and providing a down-payment on the President's promise to quadruple the number of children with access to the program. An increase of nearly \$1 billion in total Head Start funding would ensure that the infants and toddlers who were able to participate in the program because of ARRA could continue to receive its critical services.

Child Care and Development Block Grant: Increase Discretionary Funding by \$1 billion and Increase the Infant-Toddler Quality Set-Aside.

With our country facing tough economic times and a growing number of mothers entering the labor force to help support their families, child care is more important than ever to families and the well-being of our country. A recent national survey of parents conducted for ZERO TO THREE found that one in four parents reports experiencing child care-related hardships that they attribute to the economic downturn. Problems cited included not being able to afford child care, cutting back on child care hours, making other child care arrangements, and relying on a parent who was unemployed or changing work schedules to provide care.⁶

Second only to the immediate family, child care is the setting in which early childhood development unfolds for nearly 6 million children under age 3.⁷ Quality child care offers the promise of a solid future by providing our youngest children nurturance, support for early learning and language development, preparation for school, and positive social and emotional development.⁸ High quality child care is particularly important to low-income children. When care is of very high quality (as is the case with model early childhood programs), the positive effects can endure into the early adult years, particularly for children from the poorest home environments.⁹ Unfortunately, the reverse is also true: some at-risk infants and toddlers receive

care of such poor quality that it may actually diminish inborn potential and lead to poorer developmental outcomes.¹⁰

CCDBG provides critical support for low-income working families who need help in accessing child care. 28 percent of children served are infants and toddlers. While CCDBG is a lifeline for working families, it still does not meet the need. With the economic downturn, states have been faced with large deficits and program reductions. The substantial funds Congress provided for CCDBG through ARRA have helped states stave off some cuts, keep children in care, and expand services to children waiting to find care. Yet, the budget landscape in the states is still marked by serious shortfalls. I urge the Subcommittee to provide \$1 billion in additional funds for CCDBG to continue the services for children and families made possible by the ARRA funds.

Quality funds provided through CCDBG are instrumental in helping states support improvements in child care services. The infant-toddler quality set-aside (\$99.5 million for 2010) has been particularly important. ARRA provided an additional \$93.6 million to improve the quality of infant-toddler care. States have used these funds to support a variety of activities, including infant-toddler specialist networks, increased training and education providers, and purchasing materials and equipment needed to meet the unique needs of very young children.¹¹ The President's budget proposed increasing the infant-toddler appropriations set-aside. To continue state work critical to improving infant and toddler child care quality using CCDBG funds and augmented by ARRA, I urge you to include a substantial increase for the set-aside in the appropriations language.

Part C: Early Intervention for Infants and Toddlers: Increase Funding by \$400 Million

Part C of the Individuals with Disabilities Education Act (IDEA) provides federal support for early intervention programs for babies and toddlers with disabilities, assisting states as they maintain and implement statewide systems of services for eligible children, age birth through 2 years, and their families. Early intervention services under Part C may prevent or minimize the need for more costly services under Part B later in a child's life.

The science of early development highlights the remarkable opportunities to optimize child development. During the earliest months and years of life, the architecture of the brain is being built at an unparalleled rate in response to nurturing early experiences.¹² Early identification and intervention for children with developmental delays or disabilities can improve cognitive and social skills, lead to higher achievement and greater independence, and promote family competence and well-being.¹³

As with Early Head Start/Head Start and child care, ARRA recognized the importance of investing in infants and toddlers with disabilities and provided an additional \$500 million of funding for early intervention through Part C. Continuing the states' ability to reach more infants and toddlers is critical if we are to prevent or minimize developmental delays and disabilities that can be much more costly to address if left until later in a child's life. Such funds are particularly

important as states increasingly implement requirements that all infants and toddlers in Child Protective Services cases be referred to Part C. This population has a much higher rate of developmental delays, as much as 40 percent, than infants and toddlers in the population as a whole. The ability to detect delays early is critical for these most vulnerable children who face such obstacles in their lives and development. Therefore, I urge the Subcommittee to increase Part C funding by \$500 million.

Conclusion

We greatly appreciate the recognition by the Subcommittee and the Congress as a whole of the need to invest in early intervention and positive early learning experiences for at-risk infants and toddlers. I urge the Subcommittee to continue this pattern and increase investments in infants and toddlers early on, when that investment can have the biggest payoff -- preventing problems or delays that become more costly to address as the children grow older. We do not need to accept that vulnerable children will inevitably fall behind by age four and then provide special education and intensive prekindergarten services to help them play catch up. We know how to provide early intervention and positive early learning experiences to infants and toddlers that work. I hope the Subcommittee will make that initial investment to help very young children realize their potential and avoid falling behind.

¹ Shonkoff J., and Phillips, D. (Eds.) (2000). National Research Council and Institute of Medicine. *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, DC: National Academy Press.

² Heckman, J. "Investing in Disadvantaged Children Is Good Economics and Good Public Policy." Testimony before the Joint Economic Committee. Washington, DC, June 27, 2007.

³ Nurse-Family Partnership. "Proven Outcomes." Nurse-Family Partnership, 2008.

www.nursefamilypartnership.org.

⁴ U.S. Department of Health and Human Services, Administration for Children and Families. *Making a Difference in the Lives of Infants and Toddlers and Their Families: The Impacts of Early Head Start*. U.S. Department of Health and Human Services, 2002.

⁵ U. S. Department of Health and Human Services, Administration for Children and Families. *Research to Practice: Preliminary Findings from the Early Head Start Prekindergarten Follow-up*. U.S. Department of Health and Human Services, 2006.

⁶ Hart Research Associates. *Parenting Infants and Toddlers Today: Research Findings*. Washington, DC, 2009.

http://www.zerotothree.org/site/DocServer/Final_survey_report_3-11-2010.pdf?docID=10881

⁷ Shonkoff and Phillips, *From Neurons to Neighborhoods*.

⁸ J. Ronald Lally, Abbey Griffin, Emily Fencil, et al., *Caring for Infants and Toddlers in Groups: Developmentally Appropriate Practice*. Washington, DC: ZERO TO THREE, 2003.

⁹ Shonkoff and Phillips, *From Neurons to Neighborhoods*.

¹⁰ Shonkoff and Phillips, *From Neurons to Neighborhoods*.

¹¹ Schulman, K. and Blank, H. *Supporting State Child Care Efforts with American Recovery and Reinvestment Act Funds*. National Women's Law Center, April 2010.

¹² Center on the Developing Child, Harvard University. *A Science-Based Framework for Early Childhood Policy: Using Evidence to Improve Outcomes in Learning, Behavior, and Health for Vulnerable Children*. Cambridge, MA: Center on the Developing Child, Harvard University, 2007.

¹³ Shonkoff and Phillips, *From Neurons to Neighborhoods*.

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