DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2015

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

ONE HUNDRED THIRTEENTH CONGRESS

SECOND SESSION

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

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PART 7

OUTSIDE WITNESS TESTIMONY

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 2015

OUTSIDE WITNESSES TESTIMONY

TUESDAY, MARCH 25, 2014.

COAL OPERATORS AND ASSOCIATES, INC.

WITNESS

CHARLES J. BAIRD, CHAIRMAN, COAL OPERATORS AND ASSOCIATES, INC.

Mr. WOMACK. Good morning all. And it is a great honor to have you, the public witnesses, before the Labor, Health and Human Services public witness hearing.

As you know, this subcommittee provides annual appropriations to the Department of Labor, the Department of Health and Human Services, the Department of Education, and more than a dozen related agencies. With jurisdiction over such a vast scope of Federal programs, it is important to hear from many of the stakeholders and those impacted by our work, and we welcome this opportunity.

I want to thank personally all of the 22 witnesses who are with us today, and particularly my friends from the University of Arkansas. [Laughter.]

You should all know that there are multiple hearings going on simultaneously today that impact the members of this dais. And so, from time to time, they will have to unplug and move on to another hearing because of the enormous workload that the appropriators have at this time.

Before we move to our first witness of the morning, I would like to yield some time to the gentlelady from Connecticut, my friend, Ms. DeLauro.

Ms. DELAURO. Thank you so much, Mr. Chairman.

It is wonderful to be with you this morning and to be with so many folks who are here and so many people that we have had the opportunity to work with over the years and who are engaged in critical, critical efforts.

I just want to say to the witnesses today that I thank you for the hard work that you put in on behalf of America's families.

As the chairman pointed out, we have 22 witnesses. It is a wide array of important issues under the subcommittee's jurisdiction. I

think the sheer number of requests that were received to testify at this hearing testifies to how critically important labor, health, education programs under our purview are to so many people in this Nation, which is all the more reason why we should work to ensure that they are adequately funded.

Just a point which I need to make because when you adjust for inflation and population, the Labor, Health and Human Services, and Education budget has been cut by $22,500,000,000 over the last 4 years. The Budget Control Act, sequestration spending caps will take another $10,000,000,000 from this account over the next 7 years.

Now the cuts are not just numbers, but the cuts will irrevocably impact the lives of families all across the Nation, the work that you do. Medical research will be stalled. Workers will lose access to job training programs that open doors to opportunity. Fewer kids will have access to special needs education.

Less money for LIHEAP, Meals on Wheels. More low-income seniors will go cold or hungry. Families lose out on childcare, women on cancer screenings, young people on opportunities like Job Corps and Americorps.

So in the omnibus budget we passed last January, programs covered by this subcommittee received only 12 percent of the nondefense funding increase, even though Labor, HHS makes up 32 percent of the nondefense budget. And this also despite the fact that we had over $1,400,000,000 in funding holes that have to be filled.

So I am hopeful that our witnesses this morning will explain to us exactly what our present budgetary course means for your hard work and the impact that present and future cuts are having and will continue to have on the families that they meet and try to minister to.

And I know the subcommittee will listen carefully to your concerns. Many, many thanks for being here, for taking the time. And again, thank you all for what you do. You make a difference in the lives of people of this Nation, and we are grateful.

Thank you very much.

Mr. WOMACK. Thank you, Ms. DeLauro.

Before we move to the chairman, let me just remind all of the witnesses that we are going to hold fast to the 5-minute rule. And you have a light in front of you that shows when it goes yellow, my understanding that is the 4-minute mark. So you have about a minute to wrap up your comments.

Within a few seconds of the end of your 5 minutes, there will be a gentle tap of the gavel, as they do in the boxing ring to let you know that you have just a few more swings that you can make before you conclude your remarks.

We do have a very busy agenda today, and as I said earlier, the Members have a lot of other things that they are involved in. So let us please respect the 5-minute rule.

And now I would like to yield the floor to the gentleman who now has a bit of a skip in his step, the chairman of the Appropriations Committee, not because we are into regular order, but because the Kentucky Wildcats have made it to the Sweet 16 of the NCAA tournament.

And the distinguished gentleman from Kentucky, the chairman of the committee, Mr. Rogers.

Chairman ROGERS. Thank you, Mr. Chairman, and I am wearing my University of Kentucky tie, which Mr. Baird knows about.

It is my great honor, Mr. Chairman, to introduce one of my constituents to this subcommittee today. Mr. Charles Baird serves as the chairman of Coal Operators and Associates, COA, represents 39 mine operators, 137 entities that are providing goods and/or services to the mining industry throughout Central Appalachia. This outfit, COA, has been at the forefront of the challenges experienced by coal producers in the region, which he will talk about today.

This administration's relentless attack on the coal industry has brought the economy of eastern Kentucky to a grinding halt. In the last 2 years alone, nearly 8,000 miners have been laid off. It is easy to see why.

Over the last 5 years, this administration has worked to uphold its campaign promise to bankrupt anyone who intends to build new coal-fired power plants. Thanks to this administration, mining permits have languished. New rules have made it almost impossible to mine coal. Court decisions are summarily disregarded, and productive mines sit idle.

The result is that hard-working, able-bodied Americans who want to work to feed their families and provide better lives for their children have been forced into the unemployment line.

I am proud of this hard-working spirit that resides in my district and that Mr. Baird represents. It is time to stop picking winners and losers by the Government and realize that coal is our best strategy—our best strategic energy resource and keeps food on the table and utility bills low.

It keeps our people out of the unemployment line, and most importantly to our country, it keeps high-tech and manufacturing companies humming and the small businesses and communities across the country vibrant. In short, coal keeps the lights on, and we need to keep them on.

So, Mr. Chairman, I thank you for the opportunity to introduce my constituent and friend, Mr. Charles Baird.

Mr. WOMACK. Welcome to the committee, sir.

Should be a switch on the very bottom, on the base. There you go.

Mr. BAIRD. How is that? Does that work?

Mr. WOMACK. Still not working.

[Pause.]

Mr. BAIRD. Okay. Thank you very much, Chairman Womack. Mr. Rogers, good to see you again. Ranking Minority Leader Member DeLauro, I have seen you on TV. I am glad to see you in person. [Laughter.]

I am here to ask for less money, not more. So you can give these folks back here a little more money by giving MSHA less.

A couple of things I want to start on that has nothing to do with this budget—budgetary matters. But there is two things that are important.

In January, I don't think very few people in this country realized that our electric grid in the eastern United States came a hair of going down, and I am talking about the entire electricity on the

east coast of the United States. During that period of time, every coal-fired plant on the east coast was running at capacity.

These are the same coal-fired plants that some people want to have gone in the next 18 months, and there is nothing to replace it. That time is coming, and it is going to happen unless we stop what is going on here today.

And the second point is the cost of electricity. I can give you example after example of people coming to my office wanting money to pay their electric bills. Electric bills have gone out of sight, and the ones that can least afford it are the ones that are hurt the most.

So I am here to talk about the industry, though, today. There is nobody that is more interested in safety than the coal owners, their supervisory personnel, and miners. They have gotten good at it. They are very highly trained. They use sophisticated equipment.

Our employees today, particularly in eastern Kentucky, they are family. They are small mines that are run by brothers and fathers and sons and daughters. They know each other. They go shopping together with each other. They go to school together. They go on vacations together.

What is happening now because of these massive layoffs, these people don't have money to pay their car payment, to pay their house payment, to take vacations. It is an unbelievable sight.

These men and women, they are national treasures. They are used to working every day. People wonder why do you go work in the coal mine? Why would you want to go work in a coal mine on your hands and knees every day?

Well, these people do it. They have done it for generations. Grandfather, father, now them and their sons. But their only trouble is now there is no jobs.

I am here today because there is not anyone that would show up here because of retribution—the fear of retribution. MSHA now has in our district and the adjoining district, has nearly two inspectors—two to three inspectors for every single underground mine in eastern Kentucky.

Now these inspectors live with us every day. They are required to do a quarterly inspection. They arrive on the first day of the quarter, and they cease on the last day of the quarter, and then they are back the next day. I don't know if you all could function with people in your face every day, but a supervisor has to be with that person, that inspector, or what they call now "authorized representative" all the time.

We had a mine that shut down recently had not had—underground mine, understand. People go in and work underground. Had not had a single lost day for 2½ years. They shut down because of MSHA. They were just inundated all the time with inspectors.

Our number of mines have gone down dramatically, but the number of inspectors have gone up. We are getting two or three people in there all the time. On many occasions on a one section mine, you may have a dozen inspectors inspecting 10 men working. That seems a little bit asinine, but that is the truth.

They make up things as they go along, too. There is no—there is no set—the book means nothing, and I can give you example

after example. I practically would beg you to send someone out of this committee.

These folks won't talk. They are afraid to talk. They talk and they get what is called a witch team or a SWAT team of 10 inspectors coming, and there is paper flowing everywhere. And the fines are astronomical. The company I just told you that had 2½ years without a workday accident, they figured it is $15 a ton right off their gross.

So I would like to ask you to come to eastern Kentucky. We can fill the auditorium up for people to talk to you about these problems I am talking about here today.

Thank you very much. Five minutes goes awfully fast.

[The information follows:]

Written Statement of Charles J. Baird, Chairman
Coal Operators & Associates, Inc.
Before the House Committee on Appropriations
Labor, Health and Human Services, Education and Related Agencies Subcommittee
March 25, 2014

Chairman Kingston and Ranking Member DeLauro:

My name is Charles J. Baird and I am the Chairman of Coal Operators and Associates (COA), a coal industry trade association headquartered in Pikeville, Kentucky. COA's members are small and medium-sized underground and surface coal mining operations in eastern Kentucky. I appreciate the opportunity to present testimony regarding issues our operators and their employees face on a daily basis with the U.S. Department of Labor's Mine Safety and Health Administration (MSHA).

COA and our members consider the safety and well-being of our miners to be our first and foremost responsibility. Many of our members are family-run companies and the miners employed by them are family and friends and their safety is the number one priority of each and every coal company.

At the time of its creation, MSHA, coal companies and their respective employees worked together to achieve a common objective of a safe workplace, reducing workplace injuries and eliminating fatalities. In addition to MSHA, each coal producing State has enacted mine safety laws and regulations. The State agencies desire to work together, in a cooperative fashion, helped augment the various programs and initiatives undertaken by MSHA. Unfortunately, MSHA's attitude of cooperation and working together to insure the safety of each and every miner is no longer the case.

I want each of you to understand why I am appearing before you today instead of mine managers or miners. If any of our members and/or their employees appeared before you today and told you what they encounter on a daily basis from MSHA, they would be out of business and out of a job before their testimony concluded. MSHA's attitude and method of operation is very simple – any operator who wishes to discuss an issue or problem with the agency's decision or voice concerns is met with resistance and increased inspections for no other reason than an operator has said something and, quite simply, MSHA can. The above is not an isolated instance – this type of behavior is the norm, not the exception.

I make these points to indicate to you in the most serious terms possible what the miners of the eastern Kentucky coalfields are encountering on a daily basis. I am not here "crying wolf" as many people assume when an industry representative voices problems about a regulatory agency. These are real examples, real stories and real situations of an agency that has evolved from one that was created by Congress to work with States, operators and miners to create a safe working environment to one that is completely adversarial, intent on writing the most serious violations as possible regardless of the circumstances. MSHA's actions are endangering the thousands of men and women in the coalfields who still have jobs.

In 2008, the Obama Administration declared war on Appalachia and the economy of our region by deciding that they were going to do everything possible to eliminate the Appalachian coal industry. As a result, we have lost thousands of jobs, including approximately 5,000 jobs of men and women who were employed directly in the mining industry in eastern Kentucky alone. And yet MSHA continues to expand enforcement and expand their inspections to the point

where today there are more inspectors than there are mines in eastern Kentucky. Many of our mines have more inspection hours than production hours.

MSHA comes before this Subcommittee to ask for funding but they provide you with misleading information. For instance, MSHA is now classifying underground mines in Pike County, Kentucky that are closed and sealed as a "surface" mine that "need to be inspected". MSHA does not let inactive mines move to "abandoned" status in order for MSHA to show they have X # of mines they have to inspect. The Subcommittee should require MSHA to tell you the number of "authorized representatives" they have per District (rather than just identifying the number of "inspectors") and the number of active mines which produce coal in each District. Ask them to provide you with a list of inspection hours spent at each mine, by all authorized representatives (not just inspectors), and the number of citations issued and the fines levied.

As I noted above, MSHA has destroyed the very foundation upon which it was created – the intent of the Mine Safety Act and the other legislation passed by Congress regarding mine safety had always sought to create and implement cooperation, training and instruction and mutual respect among the regulated, the regulator and the States. That is gone. The leadership of MSHA has created a culture of being an adversary, of being in complete conflict with the industry they are overseeing and the very miners they are seeking to protect.

Again, the culture today has any authorized representative coming on site and writing as severe a violation as possible regardless of the circumstances. In a recent analysis, 41% of ALL S and S violations (Significant and Substantial) written were later changed to non- S and S violations (or vacated, dismissed or withdrawn) and for a three-year period (2010-2013), 29% of all the S and S violations were changed to non-S and S or vacated, dismissed or withdrawn.

Why does that occur? Because of what I said above and because there is absolutely NO accountability where this agency is concerned and no repercussions of any kind for authorized representatives to do whatever they wish.

The Committee on appropriations, just a few months ago, gave specific directions to MSHA regarding issues concerning the proposed Dust Rule. Yet MSHA has decided it is above the Congress and is requiring ventilation plans be done in such a way as to meet this proposed standard before its finalized and in contradiction to the actions of the Congress and this Committee.

Within the current budget request, MSHA has proposed eliminating the State's safety grants, one of the most effective tools for miner safety we have or ever had. Cooperation with States is emphasized in the Act, but MSHA doesn't want to cooperate. I would urge the Members of the Subcommittee to look at and consider the success and efficiency of the State programs. Again, for a coal mine, we have a complete secondary layer of inspection at the State level. But the states do things the right way. They do their job, they respect the laws under which the act, they try to work with the operators and the miners rather than considering them adversaries and I would encourage the Congress to look at letting the States be the primary regulators with MSHA in an oversite role. Every other regulatory program associated with the coal industry, and many other industries particularly from the environmental side, has a methodology for granting that State "primacy" or primary responsibility for implementing the requirements of a particular law. Our States, and Kentucky in particular, do an outstanding job with mine safety because Kentucky believes we should all

work together to insure safety versus the current MSHA attitude and I would hope the Congress would consider this approach.

I have provided you with only a small amount of information regarding the abuse of power committed by this agency on a daily basis and an endless number of examples can be provided to you in a confidential manner. I have had to do this because our operators fear retaliation and retribution that this agency can take on them and their miners if they say anything. The miners resent MSHA and fear for their jobs, not their safety. Secondly, I cannot emphasize enough that these statements should not create a doubt or question of any kind of the commitment of our mines to the health, safety and wellbeing of our miners.

I want to thank Chairman Rogers, Chairman Kingston, Ranking Member DeLauro and the Members of this Subcommittee for allowing me and, by extension, the men and women of the coal industry in eastern Kentucky, to testify before you today and to ask for your help and assistance with these issues that are destroying thousands of jobs in a part of the country that cannot afford to lose one job. The Congress and this Subcommittee is one of the few places we can turn to and request help and I pray that you will help bring this agency under control, create accountability where none currently exists, have MSHA reconsider and reevaluate this adversarial culture.

Mr. WOMACK. It does. Thank you, Mr. Baird, for your testimony.

And without objection, the full scope of your comments, as prepared, will be entered into the record.

Thank you.

Mr. BAIRD. Thank you. Thank you very much.

Ms. DELAURO. Are there any questions? Can we ask questions? Can we make comments?

Mr. WOMACK. We can ask questions. Just remember we are on a very tight timeline. So——

Ms. DELAURO. I got it. I understand.

Mr. WOMACK. The gentlelady from Connecticut.

Ms. DELAURO. Thank you very much.

And it is not really a question, Mr. Baird, but I do want to say one or two things. I appreciate your comments, and with all due respect, but I am reminded of the Upper Big Branch catastrophe that we had in mining where 29 miners died.

And there was a—that was a particular incident where there we saw a terrible record of violation. I am not suggesting that that is something that you are supportive of or interested in, but I think with regard to MSHA that we have to be very, very mindful of the safety regulations that are involved and what kind of a responsibility that we have in order to be able to protect those who do labor and toil in our mines and provide the services that they do.

So I think it should go with saying that there has been significant tragedy, and we have done some things to change that through MSHA. And I think we need to have a very strong and a continued commitment, as the omnibus appropriation bill does, in increasing funding for MSHA.

So thank you very much, Mr. Baird, for your testimony.

Mr. WOMACK. Thanks again, sir.

Chairman ROGERS. Mr. Chairman, one quick question?

Mr. WOMACK. The gentleman is recognized.

Chairman ROGERS. Mr. Baird, has the number of inspectors gone down by the same ratio as the closures of mines have taken place?

Mr. BAIRD. They are still holding job fairs. They have increased their number of authorized representatives. We have substantially less mines with the same number of inspectors.

In addition to that, we also have a layer of State inspectors that do exactly the same thing. So you are having more inspector days than work days in our mines. There are more inspectors in our mines every day than men are in our mines.

Chairman ROGERS. You would think that the Government would want to diminish paying for personnel that is not needed since those mines have closed, and yet they are still on the payroll.

Mr. BAIRD. I don't know how the Federal Government lays people off. I really don't.

Chairman ROGERS. I don't either.

Mr. BAIRD. I don't know. I have never heard of a Federal mine inspector being laid off.

Ms. DELAURO. Well, they do.

Mr. BAIRD. I know during sequester they took the State's money that the State uses to train people and for safety, and that is where it ought to go. The States are the better entity to inspect and train the miners and perform safety.

Ms. DELAURO. Would the chairman yield for a second?

Chairman ROGERS. I yield.

Ms. DELAURO. It may be that we needed more inspectors at the Upper Branch mine to deal with the raft of violations that emanated from that mine and the resultant 29 miners died. That is not a statistic. It is real-life families that suffered an enormous tragedy.

And inspection is not a bad thing. And mine safety, and I think you would concur, Mr. Baird and Mr. Chairman, because in the omnibus bill, of which you had a real role, we increased the money for MSHA and for mine safety, which is, I believe, critically important in this Nation.

And where this committee has, in fact, done some things is to underfund crucial investments in seniors and families and childcare.

Chairman ROGERS. Reclaiming my time and yielding back, Mr. Chairman.

Ms. DELAURO. Thank you.

Mr. WOMACK. The gentlelady's time has expired. The gentleman has reclaimed his time and has yielded back.

And if the gentlelady goes much further, she is going to be into the time of our next witness, who is Jody Barr from the great State of Connecticut and the Office of Administrative Faculty from Connecticut State University.

Mr. Barr, you are recognized. Remember the 5-minute rule.

TUESDAY, MARCH 25, 2014.

CONNECTICUT STATE UNIVERSITY ORGANIZATION OF ADMINISTRATIVE FACULTY

WITNESS

JODY BARR, CONNECTICUT STATE UNIVERSITY ORGANIZATION OF ADMINISTRATIVE FACULTY

Mr. BARR. Good morning, Chairman Rogers, Vice Chair Womack, Representative DeLauro, and other committee members.

My name is Jody Barr. I am the president of an organization called SUOAF, which stands for State University Organization of Administrative Faculty.

Thank you for allowing me to testify this morning.

My organization represents 760 nonteaching administrative faculty from 12 2-year colleges in Connecticut, 4 4-year universities, and the State's only online public college. Our system is also known as CONNSCU, which I will refer to it from here on.

Our 760 members work in areas that support students' education. We are admission counselors, registration officers, coaches in athletics, and members of information technology that run our 911 systems and network systems as well. Some of our members also provide financial aid counseling and counseling for our students.

CONNSCU serves more than 120,000 full- and part-time credit and noncredit students. While we provide affordable, lifelong learning, we also play a key role in the State's economy by preparing our students to meet the need of Connecticut's employers. Our 17

institutions drive the State's economy and the activity by providing an important role in Connecticut's effort to attract new businesses and industry.

Providing education is one of the most important roles of the government. While the gain from higher education is large for the individuals, it is also large for our Nation. Public investment in higher education makes our country more productive, grows our economy, and fosters good citizenship. Making higher education more broadly available also promotes economic equality and social cohesion.

Tuition at our Connecticut institutions is much lower than the average of a New England institution. Connecticut works very hard to keep our tuition affordable, but making higher education available to low-income students requires the Federal Government to be a strong partner.

I urge Congress to make higher education a priority in its spending decisions. In particular, we urge the committee to provide the highest possible funding for Pell grants. This will allow students to continue to obtain the maximum grant amount of $4,860 that is proposed in the President's budget.

The Pell grants help make higher education accessible to low-income students. Pell grants provide a consistent source of support that students need as they go throughout their college career and pursue a degree. Maintaining the current level of funding also provides our students the ability to receive supplemental income, such as work study and GEAR UP.

As I mentioned, some of our counselors are in financial aid. I have a few stories that have been shared with me about what our workers do there.

First, we have Gloria. Gloria is a first-year college student from a family that relied on low-wage jobs. After paying the bills, there was nothing left to put away for college.

Had it not been for Pell grants, State grants, scholarship money, and a work study job on campus, she would have not had the ability to pay for school. She graduated after 4 years, and today she is a financial aid counselor in our system.

Edward's parents were divorced when he was 6. Edward's mom worked as a sales clerk. Her low-wage jobs did not cover the basic needs. There were months when they lived without electricity.

Edward stuck with education because he wanted a better life. When he was a senior in high school, he applied for Federal financial aid and some scholarships. He took out Federal loans, and today he is in one of our universities and will be graduating this summer.

Angela came from a low-income family, and with the help of loans and grants, she was able to get through college and eventually on to medical school. She feels proud but is overwhelmed by over $400,000 that she owes in student loans.

She was thankful for the grants that she received and tells people that without the Federal grant money, she would never have been able to achieve her dream of becoming a doctor.

These students' lives were transformed by their ability to attend college. Their futures are brighter because the Federal Government made an investment in their education. But these kids are not the

only winners. Our Nation wins when we invest on education and our workforce development.

It is critical to our long-term economic vitality that we invest in higher education and make it a priority, and I can say for myself, I am one of those people who received the, you know, Pell grant. And today I am, I guess, living the American dream with a college education.

So thank you.

[The information follows:]

Testimony of Jody Barr,
President of the State University Organization of Administrative Faculty
for the
Public and Outside Witness Hearing
of the
House Appropriations Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Tuesday, March 25, 2014

Good morning. My name is Jody Barr and I am President of the State University Organization of Administrative Faculty. I would like to thank the Committee for allowing me to testify this morning, about the need for strong federal support for higher education.

My organization represents 760 nonteaching professional staff at Connecticut State Colleges and Universities, or CONNSCU, a statewide system of 17 academic institutions including 12, two-year colleges, four universities, and the state's only fully-online public college. Our members work in a range of capacities, including admissions, registration, athletics, and public relations. Our members operate and support the technology infrastructure for the schools and maintain the 911 emergency calling systems. Importantly, some of our members provide financial aid counseling to students trying to put together the resources to start school and to complete their studies.

Connecticut State Colleges and Universities serves more than 120,000 full- and part-time, credit and non-credit students. The system provides access to affordable, lifelong learning to students. But it also plays a key role in the state's economy by preparing students to meet the workforce needs of Connecticut employers. These schools drive economic activity in their communities and play an important role in the state's efforts to attract new business and industry.

Providing education is one of the most important roles of government. While the gain from higher education is large for individuals, it is also large for our nation. Public investment in higher education makes our country more productive, grows our economy and fosters good citizenship. Making higher education available to everyone helps promote economic equality and social cohesion.

Tuition at Connecticut's public institutions is lower than the average of New England public institutions and CONNSCU struggles to keep tuition affordable in order to make higher education broadly available. But making higher education accessible to low-income students requires that the federal government be a strong partner. We urge the Congress to make higher education a priority in its spending decisions. In particular, we urge that the Committee provide the highest level of funding possible for Pell Grants; at least funding that continues the maximum grant award of $4,860 as proposed in the President's budget. Pell Grants help make higher education accessible to low-income students and also helps them to succeed by providing a consistent source of support until they achieve their degree or certificate. Pell Grants also help to reduce the amount of borrowing, so that students are saddled with less debt as they embark on their careers. Maintaining and increasing the level of other funding is also critical for Supplemental Educational Opportunity Grants, Federal Work-Study, and Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP).

As I mentioned earlier, some of our members are financial aid counselors who work with students to cobble together the resources needed to pay their tuition, buy books and pay for transportation. Below is a sample of their stories about the students they have helped.

Gloria was a first-generation college student from a family that relied on minimum and low-wage jobs. After paying the bills, there was nothing left over to put away for college. Had it not been for Pell Grants, state grants, scholarship money and a Work-Study job on campus, she would not have been able to pay for school. She graduated after four years and is now employed at a college herself. She was so thankful for the financial support that she pursued a career as a financial aid counselor so that she could help other aspiring students.

Edward's parents divorced when he was six. Edward's mom worked as a sales clerk – a low-paying job from which she did not earn enough to always cover even the most basic needs. There were months when they lived without electricity. Edward stuck with his education because he wanted to do better for himself. When he was a senior in high school he applied for federal financial aid and for scholarships. He also took out federal loans. Today, he is in college and planning to attend graduate school. Without financial aid he said, "I would probably be working a dead-end job."

Nick's father lost his job and the reality of college slipped further and further away. Nick's mom told him to keep studying to pursue his college dream. Just before his high school

graduation, Nick's father found a new job, but at a lower rate of pay. But with the help of a financial aid counselor, Nick was able to put together state grants, loans, a Merit Award and a federal Work-Study grant to pay for school.

Angela came from a low-income family. With the help of loans and grants she was able to get through college and eventually through medical school. She feels proud, but also overwhelmed by the $400,000 she owes in student loans. She is thankful for the federal and state grants she received as an undergraduate student and tells people that without federal grant money, she would have never achieved her dream of becoming a doctor.

These students' lives were transformed by their ability to attend college. Their futures are much brighter because the federal government made an investment in them and their education. But these kids are not the only winners. Our nation wins when we invest in education and the workforce development system. It is critical to our long-term economic vitality that we continue to make these investments in Pell Grants, Supplemental Educational Opportunity Grants, Federal Work Study and GEAR UP.

Thank you.

Mr. WOMACK. Thank you for your testimony.

Ms. DELAURO. Thank you.

Mr. WOMACK. Our next witness is the board chair for the Children's Environmental Health Network. Cynthia Bearer.

Welcome, Ms. Bearer.

TUESDAY, MARCH 25, 2014.

CHILDREN'S ENVIRONMENTAL HEALTH NETWORK

WITNESS

CYNTHIA F. BEARER, BOARD CHAIR, CHILDREN'S ENVIRONMENTAL HEALTH NETWORK

Dr. BEARER. Thank you. Thank you for the opportunity to testify and your leadership in protecting children's health.

My name is Cynthia Bearer. I am a pediatrician who specializes in the care of babies born prematurely and babies born with birth defects. My titles include the Mary Gray Cobey Professor of Neonatology, Division Chief of Neonatology, and Associate Chair for Research in the Department of Pediatrics at the University of Maryland School of Medicine, the oldest public school of medicine in the country.

I am here today in my role as the board chair for the Children's Environmental Health Network. I request that my testimony and my written statement be admitted for the record.

Mr. WOMACK. Without objection.

Dr. BEARER. Thank you.

Today's children are facing the distressing possibility that they may be the first generation to see a shorter life expectancy than their parents due to poor health. The modern pediatric epidemics of obesity, asthma, learning disabilities, and autism are key contributors to this trend, and for each of these conditions, a child's environment plays a role.

In 2008, the estimated cost of environmental disease in children was more than $76,000,000,000. Investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures and, therefore, healthier and more productive adults.

It is vital that the Federal programs and activities that protect children from environmental hazards receive adequate resources. We strongly urge the committee to support and expand children's environmental health programs.

One vital health agency is the Centers for Disease Control and Prevention, which continues to be faced with unprecedented challenges and responsibilities. Thank you for your support for CDC in past years. We support a funding level of $7,800,000,000 for CDC's core programs in fiscal year 2015.

The CDC's National Center for Environmental Health is particularly important in protecting the environmental health of young children. NCEH partners with public health agencies and others to bring their expertise and support to an expanding scope of environmental human health challenges. Yet in recent years, NCEH funding has been drastically cut. We urge the subcommittee to at least restore NCEH to its fiscal year 2010 funding level.

We commend you for the substantial increase the Healthy Homes and Lead Poisoning Prevention Program received in fiscal year 2014. Millions of American children remain at risk of lead poisoning, with subsequent impacts on their neurodevelopment, and need this program, which supports effective local and State efforts.

As evidence increasingly demonstrates no safe level of lead exposure for children, this funding is all the more essential. We urge a funding level of $29,000,000 in fiscal year 2015.

Asthma is an epidemic in the U.S. affecting 10 percent of our Nation's children. We urge the committee to fund the National Asthma Control Program for $28,000,000 in fiscal year 2015.

Public health officials need integrated health and environmental data so that they can protect the public health. The CDC's National Environmental Public Health Tracking Program helps to track environmental hazards and the diseases they may cause and to coordinate and integrate local, State, and Federal health agencies' collection of critical health and environmental data. Participation in the tracking network development will decline until further cuts—I am sorry, under further cuts and erase the progress we have made across the country to better link data with public health action.

The National Institute of Environmental Health Science is the leading institute conducting research to understand how the environment influences human health. Unlike other NIH institutes focused on one disease or one body system, NIEHS is charged with all diseases, all human health and body systems as they are affected by the environment, a vital and monumental charge.

NIEHS plays a critical role in our efforts to understand how to protect children. CEHN recommends that $717,000,000 be provided for NIEHS's fiscal year 2015 budget.

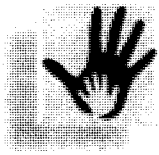
The Children's Environmental Health and Disease Prevention Research Centers, jointly funded by the NIEHS and EPA, also plays an important role in discovering the links between prenatal exposures to environmental contaminants and outcomes of pregnancy and children's outcomes. Several centers have established longitudinal cohorts, which in some cases are more than 10 years old, and they present a vital and important resource to continue this research.

The network is concerned that inadequate funding may result in the loss of these valuable cohorts. We urge the subcommittee to support these centers at $33,000,000 in fiscal year 2015.

In conclusion, our Nation's future will depend upon its future leaders. Protecting children from harmful chemicals in their environment will result in healthier children with brighter futures, an outcome we can all support.

Thank you for the opportunity to testify.

[The information follows:]



Children's
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March 25, 2014

Testimony presented by Cynthia Bearer, M.D., Ph.D., FAAP
on behalf of the Children's Environmental Health Network
before the Subcommittee on Labor, Health & Human Services, Education & Related Agencies, United States House Committee on Appropriations

On behalf of the Network, I thank you, Chairman Kingston and Ranking Member DeLauro, for this opportunity to testify and for your ongoing concern about environmental health risks to children. My testimony and the statement I am submitting for the record focus on key programs and activities that safeguard the health and future of all of our children:

- Centers for Disease Control and Prevention ($7.8 billion), especially the National Center for Environmental Health ($181.1 million) and its programs, including:
    - Healthy Homes and Lead Poisoning Prevention Program ($29 million)
    - National Asthma Control Program ($28 million)
    - National Environmental Public Health Tracking Program ($40 million)
- National Institute of Environmental Health Sciences (NIEHS) ($717.7 million), especially the Children's Environmental Health Research Centers ($33 million)
- Pediatric Environmental Health Specialty Units (PEHSUs) ($2 million)

The Children's Environmental Health Network (CEHN) was created more than 20 years ago by concerned pediatricians and researchers with a goal of protecting the developing child from environmental health hazards and to promote a healthy environment.

Today's children are facing the distressing possibility that they may be the first generation to see a shorter life expectancy than their parents due to poor health. Key contributors to this trend are the modern pediatric epidemics of obesity, asthma, learning disabilities, and autism. For all of these conditions, the child's environment plays a role in causing, contributing to or mitigating these chronic conditions. The estimated costs of environmental disease in children (such as lead poisoning, childhood cancer, and asthma) were $76.6 billion in 2008.[1]

Investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures.

Additionally, protecting our children -- those born as well as those yet to be born -- from environmental hazards is truly a national security issue. When we protect children from harmful chemicals in their environment, we help to assure that they will reach their full potential. We have a responsibility to our nation's children, and to the nation that they will someday lead, to provide them with a healthy environment. American competiveness depends on having healthy, educated children who grow up to be healthy productive adults. Thus it is vital that the Federal programs and activities that protect children from environmental hazards receive adequate resources. We strongly urge the Committee to support and expand children's environmental health programs. Key programs in your jurisdiction deserving your support include:

Centers for Disease Control and Prevention (CDC)

As the nation's leader in public health promotion and disease prevention, the CDC should receive top priority in federal funding. CDC continues to be faced with unprecedented

[1] Trasande, Liu Y. "Reducing The Staggering Costs Of Environmental Disease In Children, Estimated At $76.6 Billion In 2008, *Health Affairs*. No. (2011): doi: 10.1377/hlthaff.2010.1239

challenges and responsibilities. CEHN applauds your support for CDC in past years and urges you to support a funding level of $7.8 billion for CDC's core programs in FY 2015.

The **National Center for Environmental Health (NCEH)** is particularly important in protecting the environmental health of young children. Current research is uncovering the extensive role that environment plays in human health and development. As a result, NCEH partners with public health agencies and a wide range of other organizations to bring their expertise and support to an expanding scope of environmental-human health challenges. NCEH's programs are key national assets. Yet in recent years, NCEH funding has been drastically cut. We urge the Subcommittee to at least restore NCEH to its FY2010 funding level of $181.1 million.

We were deeply concerned with the FY 2012 gutting of the **Healthy Homes and Lead Poisoning Prevention Program** and we commend you for the substantial increase the program received in FY2014. This program helps to prevent lead poisoning and helps children who have already been exposed to lead. Much more needs to be done just to return it to FY 2011 levels. Millions of American children remain at risk of lead poisoning and need this program, which supports effective local and state efforts. As evidence increasingly demonstrates no safe level of lead exposure for children, this funding is all the more essential. We join with the National Safe and Healthy Housing Coalition to urge a funding level of $29 million in FY 2015.

NCEH's **National Asthma Control Program** not only has greatly increased data collection about this rampant epidemic but it also encourages states to use evidence-based approaches to reduce costs and improve outcomes for people living with asthma. Asthma is an epidemic in the U.S., affecting 10% of our nation's children. We urge the Committee to fund this vital program at $28 million in FY 2015.

Public health officials need integrated health and environmental data so that they can protect the public's health. The CDC's **National Environmental Public Health Tracking Program** helps to track environmental hazards and the diseases they may cause and to coordinate and integrate local, state and Federal health agencies' collection of critical health and environmental data. Participation in the tracking network development will decline under further cuts and erase the progress we have made across the country to better link data with public health action.

National Institute of Environmental Health Science (NIEHS)

NIEHS is the leading institute conducting research to understand how the environment influences human health. Unlike other NIH Institutes focused on one disease or one body system, NIEHS is charged with all diseases, all human health and body systems, as they are affected by the environment – a vital and monumental charge. NIEHS plays a critical role in our efforts to understand how to protect children, whether it is identifying and understanding the immediate impact of chemical substances or understanding childhood exposures that may not affect health until decades later. CEHN recommends that $717.7 million be provided for NIEHS' FY 2015 budget.

Children's Environmental Health Research Centers of Excellence

The Children's Environmental Health & Disease Prevention Research Centers, jointly funded by the NIEHS and the U.S. Environmental Protection Agency (EPA) and located at research institutions across the nation, play a vital role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets, these centers are generating invaluable research. For example, these centers conducted the recent research that

found links between prenatal exposures to either a common air pollutant or a common pesticide to lower IQs and poorer working memory at age 7.

Several Centers have established longitudinal cohorts, which in some cases are more than 10 years old. The ability to look for linkages between exposures and health outcomes in infants, toddlers, and, now, adolescents, is vital. If these cohorts are disbanded due to funding cuts, at best it will take years and untold resources before it is possible to replicate them. Few if any longitudinal cohort studies on adolescents, puberty and environmental exposures exist. The Network is concerned that inadequate funding may result in the loss of these valuable cohorts. We urge the Subcommittee to support these centers at $33 million in FY 2015.

Pediatric Environmental Health Specialty Units

Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network for parents and clinicians around the nation. They are funded jointly by the Agency for Toxic Substances and Disease Registry (ATSDR) and the EPA with a very modest budget. PEHSU professionals provide medical consultation to health care professionals from individual cases of exposure to advice regarding large-scale community issues. PEHSUs also provide information and resources to school, child care, health and medical, and community groups and help inform policymakers by providing data and background on local or regional environmental health issues and implications for specific populations or areas. We urge the Subcommittee to fully fund ATSDR's portion of this program in FY 2015.

In conclusion, our nation's future will depend upon its future leaders. Protecting children from harmful chemicals in their environment will result in healthier children with brighter futures, an outcome we can all support. Thank you for the opportunity to testify.

Mr. WOMACK. Thank you, Dr. Bearer.

Our next witness is the national coordinator for the, excuse me, the Elder Justice Coalition, Robert Blancato.

Did I get that name correct?

Mr. BLANCATO. Close, Mr. Chairman. Blancato.

Mr. WOMACK. Blancato. I stand corrected. The floor is yours, sir.

TUESDAY, MARCH 25, 2014.

ELDER JUSTICE COALITION

WITNESS

ROBERT BLANCATO, NATIONAL COORDINATOR, ELDER JUSTICE COALITION

Mr. BLANCATO. Thank you, Mr. Chairman, Ranking Member DeLauro.

On behalf of the Elder Justice Coalition, a bipartisan, 3,000 member organization, we thank you for the opportunity to testify in support of the Department of Health and Human Services proposed Elder Justice Initiative in the amount of $25,000,000.

My topic has been and must always be a bipartisan issue—preventing elder abuse, neglect, and exploitation. Today, we ask the subcommittee to provide the necessary funding in a bipartisan fashion as part of the solution to the real national disgrace of elder abuse.

There are more than 6 million victims of elder abuse, or roughly 1 in every 10 persons over 60. Victims of elder financial abuse lose an estimated $2,900,000,000 a year, which can include entire life savings. Other data points to a 16 percent increase in reported cases. Yet for every elder abuse case known to agencies, 24 cases are unknown.

The $25,000,000 requested in the President's budget for an Elder Justice Initiative, which, if approved by Congress, would be the first direct appropriation for the bipartisan Elder Justice Act, sponsored in the House by Congressman Peter King. The funding request includes $13,800,000 for Adult Protective Services, including an APS national data system and technical assistance, and national demonstration grants to both enhance APS data systems the development of program standards and a full evaluation of APS practices.

$11,200,000 for research, including elder abuse screening and to establish a better knowledge base about elder abuse, neglect, and exploitation.

Data collection is important. The lack of good data has hurt the elder abuse field and our ability to target efforts to prevent abuse. Data often drives dollars. For elder abuse to effectively compete for resources, we must have a good system to collect and analyze data.

We support the development of APS program standards. Interventions for victims of elder abuse are far more complicated than for younger victims of abuse and family violence. To be effective, APS programs must have consistency and quality on a national basis.

Elder abuse is happening in all States and districts, and in some cases, an older person can be victimized in more than one State.

This initial investment of $25,000,000 means existing Federal resources could be used more efficiently while also responding to elder abuse with a systematic approach. This and slowing future victimization is a solid return on investment.

Why else is this money an investment? According to the National Center on Elder Abuse, the direct medical costs associated with elder abuse now exceed $5,000,000,000. Victims often end up having to turn to other Federal programs, especially Medicare and Medicaid, and for financial abuse victims, they may require other assistance, including income support.

Some of this can clearly be avoided and savings achieved for these programs if we make this investment today. Elder abuse victims are household names like Mickey Rooney or the late Brooke Astor. We testify for them today, but also for those who are not household names. The voices we don't hear are the ones who need a voice that you can listen to today.

I said that elder justice is a bipartisan issue. Leaders have included Senator Hatch, Representative King, as well as former Senator Lincoln and Representative Emanuel, to name a few. Again, on a bipartisan basis, this Congress reauthorized the Violence Against Women Act. The reality is elder abuse is also a women's issue. The average victim is an older woman living alone between 75 and 80 at a time when the Census reports that almost 50 percent of all women over 75 now live alone. Another reason to act now.

If 1 in 10 seniors in your district were victims of crime, you would likely respond by seeking more support for law enforcement as first responders in the fight against crime. Elder abuse hits 1 of every 10 seniors. Let us give needed support to Adult Protective Services who are the first responders for elder abuse.

Our coalition also supports funding the Social Services Block Grant, the only current funding source for Adult Protective Services today, at the level proposed in the President's budget.

Just as 40 years ago when witnesses came to the subcommittee seeking initial funding for the Child Abuse Prevention and Treatment Act of 1974, we come today asking for this initial $25,000,000 for elder justice. What is common? A victim of child abuse, like a victim of elder abuse, is never the same.

The role of Government should always be to help the vulnerable of all ages. Elder justice warrants considerably more than the requested $25,000,000. The Elder Justice Act includes increased support for long-term care ombudsmen, assisting nursing home residents, and funding forensic centers important to the prosecution of abusers.

Since these are not included, please view the $25,000,000 as a floor to build on, not a ceiling. We look forward to working with you on ensuring that this first-time dedicated appropriation for elder justice provides us with the best possible value and positive outcome.

And Mr. Chairman, I request that my full statement, as well as some of our coalition members' statements, be included in the record.

Thank you very much.

[The information follows:]

Robert B. Blancato

National Coordinator

Elder Justice Coalition

Chairman Kingston, Ranking Member DeLauro:

On behalf of the Elder Justice Coalition, a bipartisan 3000 member organization, we thank you for the opportunity to testify in support of the Department of Health and Human Services' proposed Elder Justice Initiative in the amount of $25 million.

My topic has been and must always be a bipartisan issue: preventing elder abuse, neglect and exploitation. Today, we ask this Subcommittee to provide the necessary funding in a bipartisan fashion as part of the solution to the national disgrace of elder abuse.

Elder abuse in America is real.

There are more than six million victims of elder abuse, or roughly one of every ten persons over 60. Victims of elder financial abuse lose an estimated $2.9 billion a year which can include entire life savings. Other data points to a 16% increase in reported cases. However, a New York State study said for every elder abuse case known to agencies, twenty-four were unknown.

We strongly support the $25 million requested in the President's FY 2015 budget for an Elder Justice Initiative. This proposed funding level, if approved by Congress, would be the first direct appropriation for the bipartisan Elder Justice Act sponsored in the House by Congressman Peter King.

The funding request includes:

- $13.8 million for Adult Protective Services, including an APS National Data System and Technical Assistance and national demonstration grants to both enhance APS data systems and development of program standards;
- $1.2 million for a national evaluation of Adult Protective Services;
- And, $10 million for research including elder abuse screening and to establish a better knowledge base about elder abuse, neglect and exploitation.

We support the emphasis placed on data collection. The lack of good data has hurt the elder abuse field and our ability to target efforts to prevent abuse. Data often drives dollars. For elder abuse to compete effectively for resources, we must have a good system to collect and analyze data. This appropriation will also help assess who are the most likely perpetrators and victims and direct resources to those who are most vulnerable.

We support the development of APS program standards. Interventions for victims of elder abuse are far more complicated than for younger victims of abuse and family violence. To be effective, APS programs must have consistency and quality on a national basis. Elder abuse is happening in all states and districts and in some cases an older person can be victimized in more than one state.

This initial investment of $25 million will allow existing federal resources to be used more efficiently while also responding to elder abuse with a systematic approach. A more coordinated use of other federal funds for elder abuse prevention and slowing future victimization is a solid return on investment.

Why else is this an investment? According to the National Center on Elder Abuse, the direct medical costs associated with elder abuse now exceed $5 billion. Victims often end up having to turn to other federal programs, especially Medicare and Medicaid, and for financial abuse victims they may require other assistance including income support. Some of this can clearly be avoided and savings achieved for these programs if we make this investment today.

Elder abuse victims are household names like Mickey Rooney or the late Brooke Astor. We testify for them today but also for those who are not household names. The voices we don't hear are the ones who need a voice that you can listen to today.

I said that elder justice is a bipartisan issue. Leaders have included Senator Hatch, Representative King, as well as former Senator Lincoln and Representative Emanuel to name a few. Again on a bipartisan basis this Congress reauthorized the Violence Against Women Act. The reality is that elder abuse is a women's issue. The average victim is an older woman living alone between 75 and 80. In fact, many are so vulnerable to abuse with the Census reporting that almost 50 percent of all women now live alone. We must act now to get resources into elder abuse prevention.

If one in ten seniors in your District were victims of crime, you would likely respond by seeking more support for law enforcement as first responders in the fight against crime. Elder abuse hits one out of every ten seniors. Let us give needed support to Adult Protective Services who are the first responders for elder abuse.

Our Coalition also supports funding the Social Services Block Grant at the level proposed in the President's budget, the only funding source for Adult Protective Services today.

Today we ask for at least $25 million for elder justice, just as 40 years ago witnesses came to this Subcommittee seeking initial funding for the Child Abuse Prevention and Treatment Act of 1974. What is common? A victim of child abuse, like a victim of elder abuse, is never the same. The role of government should always be to help the vulnerable of all ages.

Elder justice warrants considerably more than the requested $25 million. The Elder Justice Act deals even more comprehensively with elder abuse with increased support for long term care ombudsmen assisting nursing home residents to funding forensic centers important to the prosecution of abusers. Since these are not included, please view the $25 million as a floor to build on, not a ceiling. We look forward to working with you on ensuring that this first time appropriations for elder justice provides us with the best possible value and positive outcomes.

Mr. WOMACK. Without objection, so ordered.

Thank you, Mr. Blancato, for your testimony.

Our next witness, David Bradley, executive director, National Community Action Foundation.

Mr. Bradley, the floor is yours, sir.

TUESDAY, MARCH 25, 2014.

NATIONAL COMMUNITY ACTION FOUNDATION

WITNESS

DAVID BRADLEY, EXECUTIVE DIRECTOR, NATIONAL COMMUNITY ACTION FOUNDATION

Mr. BRADLEY. Thank you, Mr. Chairman and Ranking Member DeLauro and other members of the subcommittee.

I appreciate the opportunity to talk to you about the Community Services Block Grant and its funding needs and other needs of the program. I do that with recognition of deep appreciation of how important this subcommittee has been for CSBG over the years.

As one who has been involved with CSBG since the opening seconds, this subcommittee, under Republicans and Democrats, has been very fair, very honorable, very forthcoming in taking a hard look and making responsible decisions for the Community Services Block Grant.

I have three things, three requests of the subcommittee in my testimony. Number one is to reject the administration's 50 percent cut in the program. You did last year. You did the year before. You rejected that. I would ask you once again to reject the administration's desire to cut the program in half.

Second is treat the program fairly. Take a hard look at it, make the best decisions that you can on the Community Services Block Grant. We are serving 12.5 million people a year turn to these agencies, 98 percent of the counties. In every one of the Members' districts, there are some innovative, creative, necessary programs, linkages, and partnerships occurring that I think make communities better and stronger and give people hope and opportunity.

And the third thing that I will mention is that there are ways that the subcommittee can help us make the program more effective, more efficient, and that involves making sure that our Federal partners and our State partners are doing things that they need to do to get the money out the door on time, that we do not have financial problems locally because the Feds have not gotten money out or the States are sitting on money. There are things that we can do to create, I think, a more efficient, more effective environment.

As I said earlier, we are serving about 12.5 million people. And 2014 marks the 50th anniversary of the war on poverty and the Great Society, and there is lots and lots of discussions about poverty in America these days.

This program, which started—the one I wrote, started in 1981 and has its roots back to 1964, every time that we have been involved with the Community Services Block Grant, we have tried to improve it. We have tried to make it more accountable, more responsive, more effective, performance driven.

Yet each one of these agencies still has one-third, one-third, one-third makeup on their board. It is the only program, I think, before the subcommittee that has local officials mandated to be on the board, as well as low income and the private sector.

Poverty has changed over the last 50 years, and a typical person served, typical client that deals with community action agencies today is a working mother whose income remains below the Federal poverty line.

I can look at Members here, and I can look at Congressman Joyce and know that your agency in Ashtabula used their Community Services Block Grant money to meet that need for truck drivers, for a truck drivers training school, because that is where the jobs were. And it was only CSBG that provided the glue to bring in all the partners and get that done.

I can look at Congresswoman DeLauro and know that lots of the veterans programs going on in your district, particularly homeless, single—single veterans, their needs, their unique needs are being met by Community Services Block Grant money.

So the program is tailored to nearly 1,000 communities. It is doing the, I think, the needs, the necessary needs that we have and meeting the necessary needs in these programs. And we are also using the Community Services Block Grant money to provide the innovative needs that otherwise would go unmet.

If Congressman Honda were here, I would talk about the coordination of the faith-based organizations that receive CSBG money in his district that has made a world of difference on food security in his areas.

So, again, my summary is, one, hard look at the program, and I think you will choose again, I hope, to reject the administration's proposed cuts. Two, treat it fairly. Make the best decisions you can. And three, as the bill emerges, help us make sure that our Federal and State partners make the program operate the most efficiently and effectively it can.

Good luck on all your considerations.

[The information follows:]

Testimony of David A. Bradley
Executive Director, National Community Action Foundation, Washington, DC
To the Subcommittee on Labor, Health and Human Services, Education and Related Agencies
US House Committee on Appropriations March 25, 2014

Mr. Chairman, Ranking Member DeLauro and distinguished Members, I am very grateful to be invited to appear before you to express the views of America's local Community Action Agencies on the FY 2015 Budget for the Community Services Block Grant (CSBG) in the request for the Health and Human Services Department Office of Community Services. I want to offer our views on the reasons Congress should again reject the requested 52% cut and also to urge your support for restoring the 2009 funding level, $700 million, so that community action can meet the even faster-growing demands from those who need a "hand up" to escape poverty.

The National Community Action Foundation represents the nation's 1060 local community-based organizations that are funded through CSBG. First, I have come to express the profound gratitude for rejecting the draconian cuts proposed in the Budgets of recent years. I urge you to reject the same proposal to cut the program in half in 2015.

The Community Action Network is recognized as the go-to institution for low-wage working families, retirees struggling to remain independent and parents seeking a more secure, middle-class future for their children. Community Action Agencies (CAAs) are primarily private corporations, and the 15-20% that are local government agencies do not function like a typical human services agency. In economically challenging times like these, our members see hundreds of thousands of new clients, formerly working, once 'middle class' citizens who risk losing everything when their jobs are gone.

The families and individuals Community Action Agencies serve: Half the over 6 million households served are families with children at home. Six million children make up nearly half all CAA program participants; two-thirds are of school age, more than 1/3 are living with two parents, the rest with just one parent, typically their mother. Altogether, In 2012 CAAs served more than 13 million low-income individuals.

Income: More than two-thirds of participants in programs had incomes at or below the federal poverty guideline when they came to their CAA, and half of that group had incomes that were below one-half of the amount that would qualify them as 'in poverty'.

About 31% of the households served live on retirement income, while 24% have no income other than their wages. Five percent come to their CAA with no income at all, because our members are the first line of defense against destabilizing personal crises like job loss, illness, divorce or loss of a breadwinner.

The Community Action approach has two broad goals:

1. To develop economic and social opportunities in the community through partnerships and investments, and
2. To help the most economically disadvantaged local citizens access those opportunities so they may become more self-sufficient.

What CAAs do: Community Action Agencies promote self-sufficiency; their programs support individuals and families striving to use every opportunity to become economically secure while they also invest in the future of their local communities. To achieve their mission of reducing poverty, the CAAs develop and manage a mix of public and private resources recently averaging

$12 Billion annually. The CSBG is the essential tool for bringing private partnerships and funding to work in the low-income community. It supports the people, resources and activities needed for the development stage of a partnership whether it is with a local employer, a dental school, or a public utility. In 2012, the Community Action Network had $**1.35 Billion** from private partners and funders that it had generated with prior year CSBG resources.

The Proposed 52% Reduction does disproportionate harm to our lowest-income communities:

- Without CSBG, there will not be any private anti-poverty organization governed jointly by low-income community residents, local government officials, and private sector leaders. The results will be
    - Fewer low-wage workers moved to stable, better paying jobs. Each year nearly 200,000 low-income workers or jobseekers succeeded in finding a job or a better-paying job or earning higher pay at their current job because of the resources and/or skill training their CAAs contributed. These results were sustained through the toughest years of the recession.
    - Lost flexibility to recognize and prevent a looming local crisis for low-wage, low-asset working families. For example, Ninth District Opportunity in Georgia recognized the growing foreclosure crisis affected low AND moderate income in 2009, and, using CSBG funds, employs a full-time former bank employee who developed partnerships with local financial institutions and helped dozens of homeowners on the brink prevent foreclosure by affordable loan modifications.

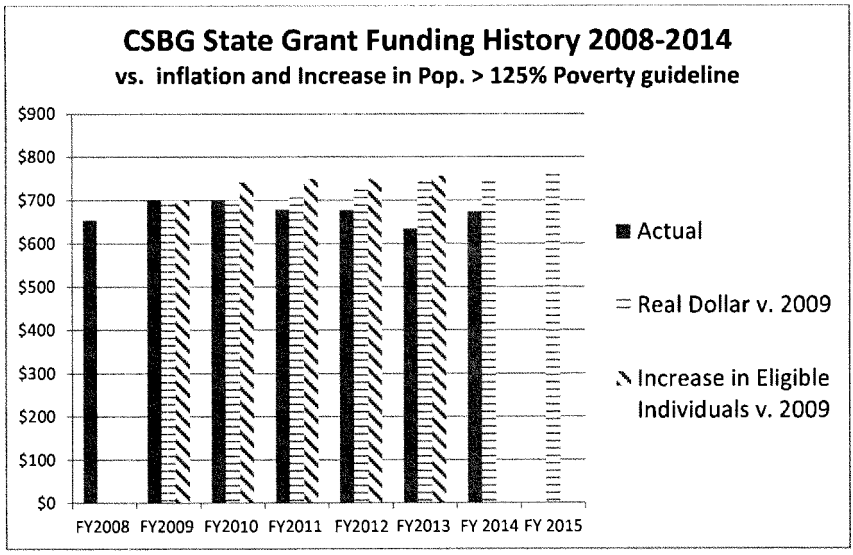
This position would have been eliminated if you had not supported a strong CSBG in subsequent years.

- Lost capacity to identify unique local opportunities to invest in long-term jobs and prepare the workers who will fill them will be left will be curtailed. For example, in Ohio, the Ashtabula Community Action Agency's business sector partners help CSBG- supported staff identify growing demand for truck drivers as an employment opportunity. The CAA is establishing a Truck Driver School in partnership with the local university where unemployed/underemployed individuals will receive Commercial Driving licenses so they can fill these jobs. The ACAA CSBG-supported staff created the partnership and recruited Ohio Means Jobs and area businesses to support and guide the initiative. This partnership could not have been developed if the organization had had only half the CSBG funds, as the Budget proposes.

Less support for Community Groups and Initiatives:

- In San Jose, the Sacred Heart Community Service, a faith-based organization that is a CAA, provided similar support and expert professional assistance for the tenant group that negotiated the assumption of responsibility for its dilapidated building when the owner abandoned the property.

Less Community Connection: CSBG supports the facilities and events that bring low-income community residents together. The South West Georgia CAA in Moultrie will close 14 rural community centers whose core operations are supported by CSBG so that other activities and programs will be accessible in remote rural areas.



Restoring the 2009 funding level

We fully recognize the demands and needs of the programs that you are asked to fund far exceed the available resources. The chart we have supplied shows actual appropriations since 2008 and also what those levels would have been if they matched either the increase in CSBG-eligible individuals (those at or below 125% FPG) or the CPI. Given fiscal realities, we would not ask for the more than 9% funding increase needed to 'keep up' with growing needs. However, restoring the CSBG to it 2009 base will allow more innovations to accelerate community economic growth and more individuals to get the increment of help they need to secure their independent future.

Mr. WOMACK. Thank you, Mr. Bradley.

Ms. DELAURO. Thank you.

Mr. WOMACK. Appreciate your testimony this morning.

Mr. JOYCE. Mr. Bradley.

Mr. WOMACK. The chair will yield to the gentleman from Ohio, Mr. Joyce.

Mr. JOYCE. Thank you, Mr. Chairman.

I know we are pressed for time, but I would like to ask one quick question.

First, I would like to thank you for your dedication and your service. Secondly, I wish you could expound to these people why it is that the CSBG grants are not duplicative of other antipoverty programs that are already consisted in this budget.

Mr. BRADLEY. Number one, it is—in a way, it is a categorical block grant. It goes to a defined population, and that we can get attacked by that. But every community has an institution that they trust, that they rely on, that they use, and that is the community action agencies. Every one of these agencies has the public sector on their board. So we are part of the local fabric.

Second, CSBG is flexible dollars. It was flexible in your district, Mr. Rogers. A third of his constituents turn to these agencies. He has got 11 in his district. These are flexible dollars that can be turned on a dime to meet local needs.

Third, Washington, a lot of talk about silos of funding. But what happens locally is that CSBG isn't a silo. It is not one program for one need. The partnership with other nonprofits, with the private sector, with Government, is unbelievable. Hundreds and hundreds of partnerships, unique partnerships across the country.

So, in that matter, who we serve, the accountability, the partnerships, and who is on the board makes CSBG a unique little program. It is only about $700,000,000, a little less. But it leverages $2, nonfederal, for every dollar that we invest in CSBG.

So thank you.

Mr. JOYCE. Thank you again for your testimony.

Mr. WOMACK. As I said at the outset of the hearing, we have Members that are having to move to other hearings that are going on simultaneously to what we have today. And so, as a matter of the chair's privilege, I am going to ask one of our speakers to speak out of order because he hails from my district, and I would like to invite to the table Dr. Charles Robinson, who will offer his testimony and perhaps an explanation as to, Ms. Lee, how the Cal-Berkeley basketball team beat our Razorbacks last night——

[Laughter.]

Mr. WOMACK [continuing]. By, I think, 12 points in the NIT tournament. We will leave that maybe for another conversation. Go Bears.

Dr. Robinson, the floor is yours, sir. Welcome.

TUESDAY, MARCH 25, 2014.

UNIVERSITY OF ARKANSAS-FAYETTEVILLE

WITNESS

CHARLES ROBINSON, VICE CHANCELLOR FOR DIVERSITY AND COMMUNITY AFFAIRS, UNIVERSITY OF ARKANSAS-FAYETTEVILLE

Mr. ROBINSON. Thank you. Thank you, Chairman Womack, Ranking Member DeLauro, and the rest of the members of the subcommittee.

I would prefer not to make any comment on the Razorbacks' recent loss, and I just would——

Mr. WOMACK. And by the way, that was earlier this morning, let me add, because that game didn't tip until about 11:15 last night.

Mr. ROBINSON. But we keep hope alive at the University of Arkansas, and we believe that next year will be a new year, and we will be in the NCAA tournament.

Thank you for this opportunity to come and to testify before this committee on behalf of Federal TRIO programs and the benefit to the University of Arkansas and northern Arkansas.

As both a scholar of integration at the University of Arkansas as well as the chief diversity officer, I know firsthand the many challenges that encumber first-generation, low-income students in search of higher education. These challenges range from poor academic preparation at the elementary and secondary levels to a lack of awareness about available college and financial aid options, to a fundamental dearth of family or peer support.

Thankfully, there are programs such as TRIO that create a pipeline from middle school all the way through postgraduate study and provide low-income, first-generation students with the necessary tools to overcome these barriers and lift their families out of poverty.

We are very fortunate at the University of Arkansas to have eight TRIO-funded grants, and they include three Talent Search programs, two Upward Bound projects, Upward Bound Math-Science, Student Support Services, and Veterans Upward Bound. Although we are proud of such a robust complement of TRIO programs on our campuses, we cannot ignore the fact that these programs respond to a very great need in our local area.

For instance, in Arkansas, the child poverty rate is 26.8 percent, significantly higher than the national rate of 20.1 percent. In fact, according to a 24-hour Point-In-Time Survey of Homeless Persons conducted by the University of Arkansas Department of Sociology, on any given night, 442 school-age children are homeless in Washington and Benton Counties.

Given the undeniable nexus between poverty and educational outcomes, it is unsurprising then that in recent years, Arkansas has experienced high school persistence rates as low as 43 percent, and college remediation rates as high as 79 percent. Taken together, these factors result in Arkansas ranking 49th among all U.S. States and the District of Columbia in the percentage of adults with bachelor's degree or higher credentials.

I share this information not to create a bleak picture of my beloved natural State, but rather to demonstrate how through tar-

geted investments in proven programs like TRIO, we can change the trajectory for many students and families, just as we have done for years at the University of Arkansas.

Now time will not permit for a full explanation of all the benefits of each of the TRIO programs. However, collectively, these programs greatly improve the college going rate of first-year and low-income students, and they improve the retention rates of these students as they diligently work towards achieving their educational dreams.

All of the TRIO programs are important, and they do a great job supporting deserving students, but I would be remiss if I did not highlight the work of one of our programs, and that is Veterans Upward Bound. Since 1993, our Veterans Upward Bound program has provided comprehensive assistance to our local military veterans, including academic assessment and classroom instruction, assistance in navigating the often confusing portfolio of disability and educational benefits provided by various Federal agencies, counseling, and assistance in post military career planning.

As 10 percent of the population within Arkansas includes military veterans, we are proud to host one of the two Veterans Upward Bound programs within the State.

In conclusion, I have been in higher education for more than two decades, and I am convinced our students, our institutions of higher education and our country needs TRIO programs like never before. With such a relatively small investment, we have been able to yield tremendous results that have helped families move out of poverty.

I applaud this subcommittee's decision to reverse the harmful cuts to TRIO last year, and on behalf of our Nation's neediest students, I hope to see continued growth in the critical set of programs that we have for the future.

Thank you.

[The information follows:]

Labor Health and Human Services, Education, and Related Agencies

Public Witnesses Hearing

Tuesday, March 25, 2014 Hearing

Testimony of Dr. Charles Robinson
Vice Chancellor for Diversity and Community
University of Arkansas - Fayetteville, Arkansas

To Chairman Kingston, Vice Chairman Womack, Ranking Member DeLauro and all of the Members of the Subcommittee, thank you for the opportunity to testify this morning about the impact and importance of the Federal TRIO Programs at the University of Arkansas and throughout North Arkansas. Specifically, I am here to stand in support of a $52 million increase in appropriations for the Federal TRIO Programs in FY 2015. As both a scholar of racial integration at the University of Arkansas as well as the chief diversity officer of the University, I know firsthand the many challenges that encumber underrepresented students in search of a higher education, whether they be students of color, students with disabilities, students of meager financial means, or students who are among the first in their families to attend college. These challenges range from poor academic preparation at the elementary and secondary levels to unawareness about the available college and financial aid options to a fundamental lack of family or peer support. Thankfully, there are programs such as TRIO that create a pipeline from middle school all the way through postgraduate study and provide low-income, first-generation students with the necessary tools to overcome these barriers and lift their families out of poverty within a single generation.

We are fortunate to have eight TRIO-funded grants at the University of Arkansas: three Talent Search programs, which work with area students in grades 7-12 to ensure that they take the

proper courses and to prepare them for college admissions testing and assist with college, scholarship, and financial aid applications; two Upward Bound projects, which provide local high school students with intensive Saturday academies and six weeks of academic coursework on our campus in the summer; Upward Bound Math-Science, which provides students with a similar experience, but with more emphasis on lab science and mathematics; Student Support Services, which provides academic tutoring, peer mentoring, financial assistance, and other supports to ensure that our low-income, first-generation University of Arkansas undergraduates persist in their studies and graduate; and Veterans Upward Bound, which works with returning servicemen and –women to help reorient them to the classroom and prepare them to make the best use of their education benefits when they pursue postsecondary education.

Although we are proud to have such a robust complement of TRIO programs on campus, we cannot ignore the fact that these programs respond to a great need in our local area. For instance, in Arkansas, the child poverty rate is 26.8%—significantly higher than the national average of 20.1%.[1] In fact, according to a 24-hour Point-In-Time Survey of Homeless Persons conducted by the University of Arkansas's Department of Sociology, on any given night, 442 school-aged children are homeless in Washington and Benton Counties. Given the undeniable nexus between poverty and educational outcomes, it is unsurprising, then, that in recent years Arkansas has experienced high school persistence rates as low as 43% and college remediation rates as high as 79%.[2] Taken together, these factors result in Arkansas ranking 49th among all U.S. States and the District of Columbia in the percentage of adults with a bachelor's degree or higher credential.[3]

[1] Kim Reeve, 2012 Arkansas Child Poverty Update (Mar. 2012): Little Rock, AR.: Arkansas Advocates for Children and Families.
[2] School Report Card, Arkansas Department of Education (2009).
[3] Chronicle of Higher Education Almanac (2013).

I share this information, not to create a bleak picture of my beloved Natural State, but rather to demonstrate how, through targeted investments in proven programs like TRIO, we can change the trajectory for many more students and families – just as we have done for years at the University of Arkansas.

As an example, the Talent Search programs sponsored at the University of Arkansas work hard to overcome the geographic isolation of the Ozark foothills to serve more than 1,800 students in 32 public schools throughout the North, Northwest, and River Valley regions of Arkansas. In 2012, these programs sent 89% of their high school seniors to college immediately following high school graduation. Of the participants who completed their first year of college, 83% persisted and are currently sophomores. Even better, those who enrolled at the University of Arkansas retained at a rate of 86%—fifteen percentage points higher than the overall institutional rate.

The success of Talent Search programs is not an aberration. Our Upward Bound and Upward Bound-Math Science programs can boast of equally strong outcomes. Between 2010 and 2012, 74% of our Upward Bound students and 83% of our Upward Bound-Math Science students enrolled in college in the fall semester following high school graduation. This is 22% and 31% higher, respectively, than the college-going rate for students in the State of Arkansas, which is 52%, and 32% and 41% higher than the college-going rate for students from the target high schools served by these programs, which have a college-going rate of just 42%. Like their peers in Talent Search, our Upward Bound and Upward Bound-Math Science alumni also have a strong retention rate, with 81% of these students persisting into their sophomore year of college.

It is important to recognize that pre-college programs alone cannot ensure that our low-income, first-generation students succeed in earning postsecondary degrees. While programs like Talent Search, Upward Bound, and Upward Bound Math-Science get them to our campus, it is programs like Student Support Services that ensures that they persist in their studies, make the best use of their federal financial aid dollars, and depart with a degree in hand and ready to contribute to the broader economy.

The low-income, first-generation students who enroll at the University of Arkansas come with great needs, as evidenced by the fact that they often arrive with less academic preparation and lower admission scores, require greater remediation, and have lower persistence and completion rates.[4] However, as a result of the *intensive* and *intrusive* counseling services provided by the Student Support Services program, hundreds of low-income, first-generation students at the University of Arkansas are outperforming everyone on campus every year. These services include academic tutoring and assistance with study skills, note-taking, and course-selection; financial aid and financial literacy workshops; and career development and graduate school preparation, just to name a few. Last year, 95.7% of the participants in our Student Support Services program either persisted to the next academic year or graduated. Indeed, participants in the Student Support Services program routinely exceed the University's graduation rates. As a result, I often look to this program as a model for the work of my own unit in promoting retention among diverse students on campus.

[4] UA Data Warehouse 2008-2009.

In discussing the TRIO programs at the University of Arkansas, I would be remiss if I did not highlight the work of Veterans Upward Bound. Since 1993, our Veterans Upward Bound program has provided comprehensive assistance to our local military veterans, including academic assessment and classroom instruction; assistance in navigating the often-confusing portfolio of disability and education benefits provided by various federal agencies; counseling; and assistance in post-military career planning. As 10% of the population within Arkansas includes military veterans, we are proud to host one of the two Veterans Upward Bound programs within the state.

I have been in higher education for more than two decades and I am convinced—our students, our institutions of higher education, our country **needs** TRIO programs. With such a small investment – $838.2 million in FY 2014 – we have been able to yield tremendous results that have helped families move out of poverty in a single generation. I applaud your Subcommittee's decision to reverse the harmful cuts to TRIO last year. On behalf of our nation's neediest students, I hope to see continued growth in this critical set of programs in the future. If we don't invest more in our lower-cost education programs, such as TRIO, we are not getting the full value out of our higher-cost education programs, like Title I and Pell Grants. Thank you for the opportunity to testify here today.

Mr. WOMACK. Thank you, Dr. Robinson.

Ms. LEE. May I very quickly?

Mr. WOMACK. The gentlelady from California is recognized.

Ms. LEE. And a graduate of the University of California.

Mr. WOMACK. And a graduate of California-Berkeley. [Laughter.]

Ms. LEE. Thank you very much. Go Bears.

Good to see you, Dr. Robinson. Thank you very much for your testimony.

Yesterday, students from Mills College, where I did my undergrad, the Upward Bound program there, they came to my office and talked about the fact that they had very little access to counselors at their high schools and said that even when they had access to counselors, their caseload prevented them from really being a successful applicant to college.

I believe you all are requesting in your testimony a $25,000,000 increase to the TRIO program. And I would just like to ask you a little bit about what that would do for the thousands of students for whom the programs really are their last resort and the last form of support for matriculation from high school to college.

Mr. ROBINSON. Absolutely. Absolutely. Programs that deal with college readiness really give students greater access to people who understand college-going culture. I mean, it is important—it is critical because we assume that students can get that at their local schools. But not all local schools are equipped with the people who have the ability or knowledge to serve these students.

And so, with an increased support for these TRIO programs, you are going to have more people who can serve more students and ultimately create a greater college-going pipeline in those particular communities that are being served by TRIO.

And so, it is a critical reality. I, on behalf of University of Arkansas, travel to the Arkansas delta and central Arkansas and southern Arkansas, and I see the need for specialized programs that serve underrepresented low-income, first-generation students.

Mr. WOMACK. Thank you. Dr. Robinson, again thank you for being here today. And go Hogs—next year.

Ms. LEE. Maybe. [Laughter.]

Mr. WOMACK. With that, I am going to excuse myself. And I am going to ask the distinguished gentleman from the Second District of Utah, Chris Stewart, to kindly take the chair.

[Pause.]

Mr. STEWART. [presiding] Okay, thank you, Mr. Chair. Happy to sit here.

And our next witness then is Lucreda Cobbs, Senior Director of Policy and Legislative Affairs from Catholic Charities.

TUESDAY, MARCH 25, 2014.

CATHOLIC CHARITIES

WITNESS

LUCREDA COBBS, SENIOR DIRECTOR, POLICY AND LEGISLATIVE AFFAIRS, CATHOLIC CHARITIES

Ms. COBBS. Good morning. Is my mike on?

Good morning, Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to speak to you today.

My name is Lucreda Cobbs, and I am the Senior Director of Policy and Legislative Affairs at Catholic Charities USA.

Today, 46.5 million people live in poverty in the U.S., the highest number since poverty was first measured. Nearly 9.3 million individuals in need, at least 2.4 million of whom were children and 1.1 million of whom were seniors, were served by a Catholic Charities agencies in 2012. Averaging these services over the course of the year, this means that in 5 minutes allotted for my spoken testimony today, Catholic Charities agencies across the country will impact the lives of more than 87 unique individuals.

When a person comes to Catholic Charities, we are not just giving a hand out. We are also giving a hand up. Many of our programs seek to help with the immediate need, but also with long-term solutions that lead to self-sufficiency.

However, these programs and those like them would not be available without essential public funding. In 2012, Catholic Charities agencies received more than $710,000,000 in Federal funding, representing 16 percent of the Catholic Charities agencies' total income. Therefore, I come to you today to discuss support for programs lifting people out of poverty and new models for maximizing the efficacy of those programs.

It is imperative that we let you know how these vital programs are making a difference in the lives of people we serve and keeping them from slipping deeper into poverty. Our ask to the subcommittee is not a specific funding amount, as Catholic Charities programs through the country receive funding from various Government funding streams, many of them under the jurisdiction of this subcommittee.

However, I appear today to stress the importance of full funding for vital programs that are helping to reduce poverty in our country and to suggest a new model for how funds can be more effective. I would like to say that cutting funding for programs is not the answer. A decline in Federal benefits and cuts and elimination of programs will only increase the numbers of those struggling to overcome poverty.

However, in this challenging funding environment, we must find new ways to address the urgent demand for long-term sustainability of the service delivery system and to better serve the millions of Americans living in poverty. To make sustainable progress in the efforts to enable greater self-reliance, we must think and act anew by examining bold revisions to social programs and policies that have been in place in our Nation for over 50 years.

So, to that end, CCUSA has proposed a policy initiative called the National Opportunity and Community Renewal Act, also known as NOCRA, which contains three policy principles which we believe will bring new and innovative ideas to the discussion.

And these three principles are, one, systems changing. Very often bureaucratic silos prevent individuals from accessing essential services that could establish their self-reliance. Recognizing the individualized nature of poverty, CCUSA seeks reform that will cut redtape, break down silos, update outdated measurements, and de-

liver support at the earliest and the most cost-effective moments of need.

Second, the market based. The nonprofit sector cannot end poverty in America working alone. By building a greater engagement with Government and the corporate sector, social services agencies can pursue innovative funding streams through new capital markets, expanded tax credits, and monetizing their saving through social impact bonds.

Results driven. As a network, we are committed to moving from measuring simple outputs to meaningful outcomes. By incorporating evaluation into the ground floor of program design and establishing a framework for producing measurable outcomes, we can ensure that Government funds are invested in what works.

Thank you for the opportunity to testify about support for Federal programs critical to lifting people out of poverty and new models for maximizing the efficacy of those programs. And I would be glad to answer any questions.

Thank you.

[The information follows:]

TESTIMONY OF LUCREDA COBBS
SENIOR DIRECTOR OF POLICY AND LEGISLATIVE AFFAIRS
CATHOLIC CHARITIES USA

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES
COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

MARCH 25, 2014

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to speak to you today.

My name is Lucreda Cobbs, and I'm the Senior Director of Policy and Legislative Affairs at Catholic Charities USA (CCUSA).

Catholic Charities agencies have a long-standing history of leading the private sector in serving those most in need at critical and vulnerable times while working tirelessly to reduce poverty in America. Catholic Charities agencies have been on the frontlines for more than a century serving those in need and empowering them to build lives of dignity and economic security. Far too often, we see the suffering of men, women, children, and seniors, who do not have access to decent, safe and affordable housing, adequate health care and nutrition, and/or adequate funding to provide for themselves and their families. We see the plight of working families whose members struggle to hold down two and three jobs just to make ends meet—yet they cannot feed their children or find affordable housing. These struggles for survival put incredible strains on family life and often contribute to the breakup of marriages and families. We see the difficulties faced by senior citizens, who are dehumanized and demoralized when they have to choose between utilities and food. In a nation as prosperous as ours, this should not be.

Therefore, I come before you today to discuss support for programs lifting people out of poverty and new models for maximizing the efficacy of those programs. CCUSA recognizes that the overall level of funding for discretionary federal programs has been set primarily by the enactment of the Bipartisan Budget Act of 2013 (**PL 113-67**); however, you will be making important decisions regarding what level of funding individual programs will receive. It is imperative that we let you know how these vital programs are making a difference in the lives of the people we serve and keeping them from slipping deeper into poverty. Our ask to this subcommittee is not a specific funding amount for programs—as Catholic Charities programs throughout the country receive funding from various government funding streams—many of them under the jurisdiction of this subcommittee. However, I appear today to stress the importance of funding for vital programs that are helping to reduce poverty in our country and to suggest a new model for how those funds can be more effective.

Today, 46.5 million people live in poverty in the U.S. – the highest number since poverty was first measured. Nearly 9.3 million individuals in need (at least 2.4 million of whom

were children and 1.1 million of whom were seniors) were served by a Catholic Charities agency in 2012. Averaging these services over the course of the year, this means that in the five minutes allotted for my spoken testimony today, Catholic Charities agencies across the country will impact the lives of more than 87 unique individuals.

Our agencies make a difference in lives of our most vulnerable neighbors by:

- **Helping individuals achieve employment and self-sufficiency.** In 2012, 62 Catholic Charities agencies helped 17,557 refugees achieve self-sufficiency, measured by stable employment and housing. Agencies helped an additional 19,277 individuals achieve employment through training, mentoring, and job search assistance programs.

- **Providing shelter for the homeless.** In 2012, Catholic Charities agencies provided housing services to more than 475,000 clients. Our agencies operated more than 230 shelters with 13,640 beds available, but also provided more than 33,000 permanent housing units to low-income families, persons with mental and physical disabilities, veterans, and other at-risk populations.

- **Sustaining the hungry.** In 2012, Catholic Charities agencies delivered more than 4.9 million meals, operated more than 1,600 food banks and pantries, and provided the critical resource of a healthy lunch for low-income children during the summer at more than 350 sites.

- **Caring for the sick and vulnerable.** Catholic Charities agencies provide counseling and behavioral health services to nearly a half million clients annually. In some communities, Catholic Charities agencies operate health clinics, reaching nearly 50,000 people, while a growing number of agencies also offer low-income dental clinics. Moreover, the majority of our agencies provide case management services to at-risk populations in their communities, offer comprehensive care to difficult to serve populations including the physically and mentally disabled, veterans, military families, victims of crime, ex-offenders, juvenile offenders, and victims of human trafficking.

While we are very proud of the work our agencies do, we are NOT McDonalds, and "one billion served" is NOT our definition of success.

When a person comes into Catholic Charities, we are not just giving a handout; we are giving them a hand up. Many of our programs seek to respond to immediate needs while also identifying long-term solutions that lead to self-sufficiency. For instance, some programs require that individuals receive financial counseling/asset development before receiving services. In addition, some agencies have launched programs that are designed to increase persistence and degree-attainment among low-income students by reducing the chance that events outside of school derail a college education. This is achieved through two distinct mechanisms: (1) holistic, personalized case management and (2) emergency financial assistance. An example of this is Catholic Charities Fort Worth's

successful Stay the Course program.

Programs like Circles of Northwest Florida work with low income individuals and families to explore the resources necessary for self-sufficiency by offering a15 week training course called *Getting Ahead in a Just Gettin'-by-World*™. This program includes Soft Skills Training and Resource Development, displaced Worker job Search support, supportive Career Coaching, Weekly Community Meetings, building and supporting intentional relationships, and training community members from diverse backgrounds on the complex issues surrounding poverty. However, these programs and those like them in the faith community would not be available without essential public funding. In 2012, Catholic Charities agencies reported receiving more than $710 million in federal government funding, representing 16 percent of the CCUSA network's total income. Therefore, through private and other public funding sources, our agencies leverage five times the federal dollars appropriated to them, making the appropriations process you are about to undertake critical to our network.

Cutting funding for programs is not the answer. The decline in federal benefits, combined with cuts to and elimination of programs will only increase the numbers of those struggling to overcome poverty.

When the workforce and economy take a hit, those being served by social service agencies are often the first to feel the impact and the last to recover. Within days of last fall's government shutdown, for example, Catholic Charities agencies were reporting the increased need in the community. Seventy-six percent of our agencies reported that their ability to deliver services was negatively impacted by the shutdown, with 31 percent reporting an increase in the number of clients coming to their doors. Similarly, our agencies immediately feel the impact of funding cuts like sequestration, and these impacts are passed directly on to their clients. Just prior to sequestration taking effect, an overwhelming eighty-seven percent of Catholic Charities agencies reported that they would be able to serve fewer clients as a result of across the board federal funding cuts.

While Catholic Charities remains committed to helping families make ends meet and find solutions to achieve self-sufficiency, our private donations can only be a part of the solution. As a nation, we cannot pull the rug out from under our nation's most vulnerable women, men, children, and seniors. We can understand having fiscal limits, but we have to take into account the reality of those living on the margins.

It is vital that government leaders work to ensure that all people have access to decent and affordable housing, access to nutritious food, access to quality and affordable healthcare, access to workforce and job training, and are able to provide for themselves and their families.

In this challenging funding environment, we must find new ways to address the urgent demand for long-term sustainability of the service delivery system and to better serve the millions of Americans living in poverty. To do so, we must use today's convergence of growing national debt, bureaucratic inefficiency and increasing demand on a strained

safety net as a catalyst for innovative changes to the service delivery system in a way that assures access to opportunity for all Americans in need.

The safety net cannot withstand the growing burden it faces. Analysis by the Brookings Institute, based on OMB and CBO economic projections, shows that the poverty rate will remain above 13 percent over the next decade, with child poverty likely to decline, but still remain above 15 percent. To make sustainable progress in the efforts to enable greater self-reliance, we must think and act anew by examining bold revisions to the social programs and policies that have been in place in our nation for over 50 years. We must look to communities across the nation that have created effective and fiscally efficient programs to address contemporary poverty issues and create national policies that allow those proven solutions to scale.

Just as the Great Depression catalyzed new innovations and social policy, Catholic Charities USA believes today's economic challenges provide an opportunity to utilize 21st century solutions to increase access to opportunity. We believe that as a country we have a responsibility to do better for those in our society who find themselves in need of assistance. To that end, CCUSA has proposed a policy initiative called The National Opportunity and Community Renewal Act (NOCRA), which contains three policy principles which we believe will bring new and innovative ideas to the discussion of how to modernize our nation's service social service delivery system and directly address the complex challenges posed by the unacceptable reality of poverty in America in the 21st century.

The three basic principles of NOCRA are:

SYSTEMS CHANGING: Very often, bureaucratic silos prevent individuals from accessing essential services that could establish their self-reliance. Recognizing the individualized nature of poverty, CCUSA seeks reform that will cut red tape, break down those silos, update outdated measurements and deliver support at the earliest and most cost effective moments of need. More specifically, CCUSA recommends:

- Developing Individual Opportunity Plans, created with the assistance of client advocates, to create poverty relief strategies that are specifically-tailored and client-driven. Case management is essential to outcomes for clients.

- Establishing tiered levels of services that prevent people from falling into poverty, help those who are receiving services reach self-reliance, and maintain a level of services for those who require long-term support to live a dignified life.

- Updating our nations' outdated federal poverty standard with modern methodology.

MARKETS-BASED: The non-profit sector cannot end poverty in America working alone. By building a greater engagement with government and the corporate sector, social

service agencies can pursue innovative funding streams through new capital markets, expanded tax credits, and monetizing their savings through social impact bonds. More specifically, CCUSA recommends:

- Creating social impact bonds that monetize the savings created by poverty prevention programs and reinvests those funds back into the community.

- Incentivizing private sector engagement beyond traditional philanthropy through Qualified Community Renewal contributions.

- Support social innovation and microenterprise efforts that enable non-profit agencies to make a profit while serving human needs.

RESULTS DRIVEN: As a network, we are committed to moving from measuring simple outputs to meaningful outcomes. By incorporating evaluation into the ground floor of program design and establish a framework for producing measureable outcomes, we can ensure government funds are being invested in what works. More specifically, CCUSA recommends:

- Gaining a deeper understanding of components to successful and scalable anti-poverty programs in communities around the country.

- Requiring data tracking technologies and systematic reporting be included as part of the initial stages of local program implementation.

Based on these principles, Catholic Charities USA is pleased to inform the subcommittee that we are supporting six pilot projects across the country to demonstrate the effectiveness of these programs. The pilots are located in Milwaukee, WI; Chicago, IL; Indianapolis, IN; Fort Worth, TX; San Jose, CA; and Honolulu, HI.

In working to reduce poverty in America, it is important to invest in what works. But in order to invest in programs that work, it is vital to know which programs are actually working to assist people on their journey out of poverty, and which are less effective. Catholic Charities USA and our network of member agencies across the country are transitioning from measuring simple outputs to gaining an understanding of outcomes. Our focus should not be on counting the number of shelter beds provided or meals supplied, but on calculating the impact our programs have on stabilizing families and strengthening self-sufficiency.

An important component of this work is our partnership with the University of Notre Dame's Lab for Economic Opportunities, or LEO. By serving as a first-of-its-kind domestic poverty lab, the Lab brings together service providers and academic researchers to perform research evaluations on anti-poverty programs. By incorporating economic research into the design of programs and determining which aspects of the program are scalable, LEO has the potential to be a game-changer in the way we determine what programs are working and making decisions to invest based on empirical scientific

research. Research programs are already underway in communities across the United States, and we look forward to sharing these results with you as they become available. Investing in what works is an essential component of holistic reform of our nation's anti-poverty efforts.

Thank you for the opportunity to testify about support for federal programs critical to lifting people out of poverty and new models for maximizing the efficacy of those programs. I would be glad to answer any questions you may have.

Mr. STEWART. Thank you, Ms. Cobbs.

The sitting chair recognizes the subcommittee chairman, Mr. Kingston. Do you have anything, sir?

Mr. KINGSTON. I just want to say broadly that Catholic Charities has a very good reputation, and you have been very succinct in the testimony. So I just appreciate your good work, and I yield back.

Mr. STEWART. All right then. Thank you, Ms. Cobbs.

Ms. COBBS. Thank you.

Mr. STEWART. We recognize Dr. John Courtney, CEO of the American Society for Nutrition.

TUESDAY, MARCH 25, 2014.

THE AMERICAN SOCIETY FOR NUTRITION

WITNESS

JOHN E. COURTNEY, CHIEF EXECUTIVE OFFICER, THE AMERICAN SOCIETY FOR NUTRITION

Mr. COURTNEY. Good morning. Thank you for the opportunity to provide testimony regarding fiscal year 2015 appropriations.

The American Society for Nutrition, or ASN, respectfully requests $32,000,000,000 for the National Institutes of Health and $182,000,000 for the Centers for Disease Control and Prevention's National Center for Health Statistics in fiscal year 2015.

ASN is dedicated to bringing together the world's top researchers in nutrition to spread the knowledge and application of nutrition. We have over 5,000 members globally. We impact over tens of thousands of health practitioners in the United States every year, and we reach over millions and millions of customers in the United States each year as well.

The NIH is the Nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent of federally funded basic and clinical research. Although nutrition and obesity research makes up less than 8 percent of the NIH budget, some of the most promising nutrition-related research discoveries have been made possible by supporting NIH and their research.

NIH nutrition-related discoveries have impacted the way clinicians prevent and treat heart disease, cancer, diabetes, and other chronic diseases. For example, U.S. death rates from heart disease and stroke have decreased by more than 60 percent, and the proportion of older adults with chronic disabilities has dropped by one third.

With additional support for NIH, additional breakthroughs and discoveries to improve the health of all Americans will be possible. Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth.

A decade of flat funding, followed by the sequestration cuts, has taken a significant toll on NIH's ability to support research. Such economic stagnation is disruptive to training, careers, and long-range prospects, and ultimately to progress. Increasing the NIH's budget to $32,000,000,000 would fully restore the funding that was

lost to sequestration and support at least 600 additional competing research project grants.

As a first step toward sustainable growth, ASN recommends a minimum of $32,000,000,000 for NIH in fiscal year 2015. NIH needs this sustainable and predictable budget growth in order to fulfill the potential of biomedical research, including nutrition research, to improve the health of all Americans.

The National Center for Health Statistics, or NCHS, housed within the Centers for Disease Control and Prevention, is the Nation's principal health statistics agency. ASN recommends a fiscal year 2015 funding level of $182,000,000 for NCHS, consistent with the President's budget request, to help ensure uninterrupted collection of the vital information and nutrition statistics that help to cover the cost for technology, information security maintenance, and upgrades that are necessary to replace the aging infrastructure of this very important program.

The NCHS provides critical data on all aspects of our healthcare system and is responsible for monitoring the Nation's health and nutrition status through surveys, such as the National Health and Nutrition Examination Survey, or NHANES. Data collected through NHANES are essential for tracking the nutrition, health, and well-being of the American population and are especially important for observing nutritional and health trends in our Nation's children.

Nutrition monitoring is critical to guide policy development in the area of health and nutrition, including food safety, food labeling, military rations, and dietary guidance, including the dietary guidelines for Americans; to evaluate the effectiveness and efficiency of nutrition assistance programs, such as the Supplemental Nutrition Assistance Program; and to monitor the prevalence of obesity and other chronic diseases in the U.S. and to track the performance of preventive interventions.

So, in closing, I would like to again thank the committee for the opportunity to present testimony, and I would also like to thank the committee for all your hard work. We know how difficult it is.

You are faced with many requests and many opportunities and many really good programs. So ASN is happy to partner with you. How can we help you to make these decisions and to advance health within the United States?

So thank you very much.

[The information follows:]

American Society for Nutrition
Excellence in Nutrition Research and Practice

March 25, 2014

Public Witness Testimony from John E. Courtney, Ph.D.; Executive Officer; American Society for Nutrition

The Honorable Jack Kingston
Chairman
Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
U.S. House of Representatives
Washington, DC 20515

The Honorable Rosa L. DeLauro
Ranking Member
Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Kingston and Ranking Member DeLauro:

Thank you for the opportunity to provide testimony regarding Fiscal Year (FY) 2015 appropriations. **The American Society for Nutrition (ASN) respectfully requests $32 billion dollars for the National Institutes of Health (NIH) and $182 million dollars for the Centers for Disease Control and Prevention/ National Center for Health Statistics (CDC/ NCHS) in Fiscal Year 2015.** ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and

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info@nutrition.org | www.nutrition.org

has more than 5,000 members working throughout academia, clinical practice, government, and industry.

National Institutes of Health (NIH)

The NIH is the nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent of federally-funded basic and clinical nutrition research. Although nutrition and obesity research makes up less than eight percent of the NIH budget, some of the most promising nutrition-related research discoveries have been made possible by NIH support. NIH nutrition-related discoveries have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. For example, U.S. death rates from heart disease and stroke have decreased by more than 60 percent, and the proportion of older adults with chronic disabilities has dropped by one-third. With additional support for NIH, additional breakthroughs and discoveries to improve the health of all Americans will be made possible.

Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth. A decade of flat-funding, followed by sequestration cuts, has taken a significant toll on NIH's ability to support research. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately to progress. Increasing the NIH budget to $32 billion dollars would fully restore the

funding that was lost to sequestration and support at least 600 additional competing research project grants. **As a first step toward sustainable growth, ASN recommends a minimum of $32 billion dollars for NIH in Fiscal Year 2015.** NIH needs sustainable and predictable budget growth in order to fulfill the full potential of biomedical research, including nutrition research, and to improve the health of all Americans.

Centers for Disease Control and Prevention National Center for Health Statistics (CDC NCHS)

The National Center for Health Statistics, housed within the Centers for Disease Control and Prevention, is the nation's principal health statistics agency. **ASN recommends a Fiscal Year 2015 funding level of $182 million dollars for NCHS**, consistent with the President's budget request, to help ensure uninterrupted collection of vital health and nutrition statistics, and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure.

The NCHS provides critical data on all aspects of our health care system, and is responsible for monitoring the nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES). Data collected through NHANES are essential for tracking the nutrition, health and well-being of the American population, and are especially important for observing nutritional and health

trends in our nation's children. Nutrition monitoring is critical to guide policy development in the area of health and nutrition, including food safety, food labeling, military rations and dietary guidance, including the *Dietary Guidelines for Americans*; to evaluate the effectiveness and efficiency of nutrition assistance programs, such as the Supplemental Nutrition Assistance Program (SNAP); and to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions.

Thank you.

Mr. KINGSTON. Actually, I did have a question, Mr. Chairman.

Mr. STEWART. Yes, sir.

Mr. KINGSTON. I wanted to make sure you are aware of TAP. Are you aware of the TAP, that is the transfer of money out of NIH to the HHS general account?

Mr. COURTNEY. I am not aware of that, no.

Mr. KINGSTON. It is $800,000,000. So while groups say we want full funding of NIH, for them not to know about the effects of TAP I think is generally part of the picture. So what I would like you to do, and I will give you some follow-up information, I would like to know what your position would be on the TAP transfer of funds.

Because we don't really know what that $800,000,000 goes to once it leaves NIH. We know it goes to general HHS spending, but it is almost like a tax within the department to various subagencies. And in the—as somebody and everybody up here supports NIH, but I can't tell you how frustrating it is for us to have groups come in here and say we want full funding for NIH and then to not be aware of TAP.

And so, I want to make sure that, you know, I am not just speaking to you, but others who, like us, support NIH.

The second thing is we have worked with Dr. Collins very closely, great respect for Dr. Collins. Yet some of the NIH grants are somewhat frivolous and nonscientific. And I have often said we want the money to go the scientists in the lab with the white jacket on, breaking down the molecular formula to cure diseases and do great things rather than fluffy political stuff.

For example, the NIH spent $8,000,000 studying if the Tea Party got tobacco money. And I would think the most anti-Tea Party person in the world would say probably not where NIH should be spending their money.

And I often hear from my NIH friends, and believe me, I am supportive of NIH. But I often hear, well, you know, we can't control all the grants. To which I say walk across the street to the Library of Congress and just tear up one or two books. It is not a big deal to a big library that has millions.

But the reality is waste is waste, and where I think we can really join forces together is to say, okay, within the NIH budget, which is limited, how can we most effectively utilize that money?

Mr. COURTNEY. Those are excellent comments, and I really appreciate that. And certainly anything we can do to improve the efficiency of the nutrition research is our primary concern. So we will definitely follow up with your office on your suggestion.

Mr. KINGSTON. And I also wanted to say that Ms. DeLauro, the ranking member, and I have both chaired the Agriculture Subcommittee, in which we do a lot of nutrition-supportive stuff. And we are happy to work for anybody who wants better nutrition in America.

So it is kind of interesting that physically that subcommittee is a couple of doors down, but the subject matter just totally overlaps with what we are doing here. And so, we are very appreciative of what you do.

Mr. COURTNEY. Well, thank you so much for all that you are doing to improve nutrition research. Thank you very much for your comments.

Mr. STEWART. Thank you, Chairman Kingston.

Dr. Courtney, thank you.

The next witness in is Jamitha S. Fields, Vice President, Community Affairs, for Autism Speaks.

TUESDAY, MARCH 25, 2014.

AUTISM SPEAKS

WITNESS

JAMITHA S. FIELDS, VICE PRESIDENT, COMMUNITY AFFAIRS, AUTISM SPEAKS

Ms. FIELDS. Thank you for the opportunity to talk with you today about autism.

I am Jamitha Fields, Vice President for Community Affairs at Autism Speaks. Autism Speaks is the world's leading autism science and advocacy organization. Our goal is to change the future for all of those who struggle with autism spectrum disorders.

We fund research, raise public awareness, and advocate for the needs of individuals with autism and their families. We have invested over $400,000,000 in this effort, and we are committed to continuing our work.

Autism and autism spectrum disorders are both general terms for a group of complex disorders of brain development. There are some with autism who need very little intervention, but there are others who cannot speak or care for themselves and will need lifelong assistance.

Autism is the fastest-growing developmental disability in the United States. The number of children on the spectrum has risen so sharply that American families are now 10 times more likely to have a child with autism than just a decade ago.

The annual estimated cost to society is $137,000,000,000. For families, the out-of-pocket costs for autism treatment and therapies can rise to $60,000 a year, and those costs are just out of reach.

Since the enactment of the Combating Autism Act, the proportion of infants and toddlers being screened for autism spectrum disorders is rising. The proportion of children diagnosed by age 3 is growing, and there are continuing improvements in decreasing the time between diagnosis and intervention.

Yet while more children are being diagnosed earlier, more children are not. Studies demonstrate that signs of autism emerge as early as 6 to 12 months. Thanks to research, we have effective tools for screening children for autism risk as early as 1 year. Yet the average age of diagnosis is about 4 to 5 years.

The situation in some ethnic and low-income communities is even more troubling. Multiple studies have shown that black and Latino children are under-identified, diagnosed significantly later, and once diagnosed, they receive poor quality of care. That is why Autism Speaks is focusing on the Early Access to Care initiative, which seeks to reduce the age of diagnosis and increase access to high-quality early intervention for all children on the autism spectrum.

We have partnered with the CDC, the American Academy of Pediatrics and others to educate communities about the disparities

and carry out evidence-based strategies to bring about effective change. Improving this unacceptable situation will take the combined efforts of public and private partners, including leaders like you who can help focus public attention on issues like this.

The earlier children are identified, the earlier they are able to receive early intervention services. Evidence-based early intervention services have shown to reduce the core symptoms of autism, improve IQ and daily functioning, reduce the cost of lifelong care by two-thirds. Considering the cost of autism over the life span is estimated at $2,300,000, those are significant savings.

This is just one example of a pressing need related to autism. The funding provided through this subcommittee is just one piece of the puzzle. While we know more than we did a decade ago, there is still so much more to discover.

Boys are four to five times more likely to have autism than girls. Why? What accounts for the differences between those who are eventually able to live independently versus those who will require lifelong assistance?

As I hear from the families struggling to find and pay for appropriate services, treatments for their children, struggling to address the hazards of wandering, and struggling to find housing and jobs for fast-growing populations of adults with autism, I know there is much more to do. We need leadership now more than ever. We need to start looking not just at the cost of what we are doing, but also the cost of not—the cost of not doing more.

Thank you for the work you have done so far, and I hope that we can count on you to make a continued difference.

[The information follows:]

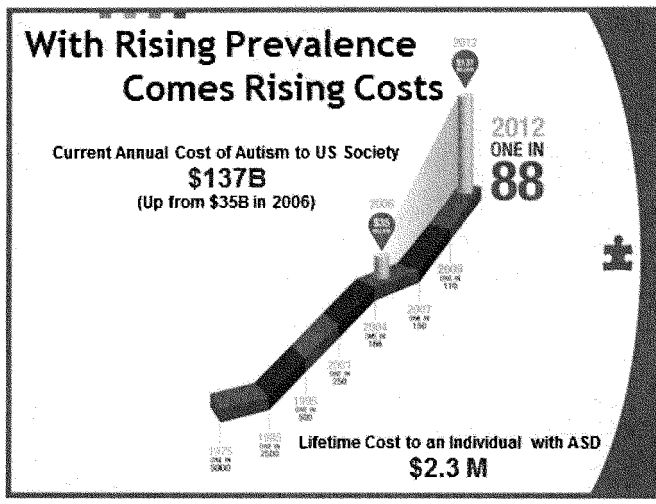
TESTIMONY PRESENTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES BY JAMITHA FIELDS, VICE PRESIDENT FOR COMMUNITY AFFAIRS AT AUTISM SPEAKS

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to offer testimony on the importance of continued funding for autism. The Combatting Autism Act authorizes $22 million for autism activities within the Centers for Disease Control and Prevention's (CDC); $48 million for autism research, treatment and training activities at the Health Research and Services Administration's (HRSA); and $161 million for research and coordination at the National Institutes of Health (NIH).

I am Jamitha Fields Vice President for Community Affairs at Autism Speaks. Autism Speaks is the world's leading autism science and advocacy organization. Our goal is to change the future for all who struggle with autism spectrum disorders. We are dedicated to funding research into the causes, prevention, treatments and a possible cure for autism. We strive to raise public awareness about autism and its effects on individuals, families, and society and we advocate for the needs of individuals with autism and their families. We have invested over $400 million in this effort and we are committed to continuing our work.

Autism and autism spectrum disorder (ASD) are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. There are some with autism who need very little intervention but there are others who cannot speak or care for themselves and will need lifelong assistance.

Autism is the fastest growing developmental disability in the United States. The number of children on the spectrum has risen so sharply that American families are now ten times more likely to have a child with autism than just a decade ago. The estimated annual cost to society is $137 billion a year. For many families, the out-of-pocket costs for autism treatment and therapy, which can rise to $60,000 a year, are out of reach. But autism is not just a healthcare issue. The economic burden associated with ASD can be measured across multiple sectors of our society, particularly education.



Since the enactment of the Combating Autism Act (CAA) in 2006 and its reauthorization in 2011, federal agencies, in partnership with Autism Speaks and others in the private sector, have made strides in addressing one of our nation's top health priorities. The law has increased the number, scope, pace and coordination of autism research, surveillance, public education and professional training. As a result, the proportion of infants and toddlers being screened for ASD is rising; the proportion of children diagnosed by age three is growing; and there are continuing improvements in decreasing the time between diagnosis and intervention.

That is good news but more needs to be done.

While more children are being diagnosed earlier, most children are not. Studies demonstrate that signs of autism emerge as early as 6 to 12 months. Thanks to research, we have effective tools for screening children for autism risk as early as one year. Yet according to CDC, the average age of diagnosis is 4-5 years. The situation in some ethnic and low income communities is even more troubling. Multiple studies have shown that black and Latino children are under identified, diagnosed significantly later, and once diagnosed, they receive poorer quality of care.

That's why Autism Speaks is focusing on the Early Access to Care initiative which seeks to reduce the age of diagnosis and increase access to high-quality early intervention for *all* children on the autism spectrum. We have partnered with CDC, the American Academy of Pediatrics and others to educate communities about the disparities and carry out evidence based strategies to bring about effective change. Improving this unacceptable situation will take the combined efforts of public and private partners including families, healthcare professionals,

educators, autism advocates in every community and leaders like all of you who can help focus public attention on issues like this.

The earlier children are identified, the earlier they are able to receive early intervention services. Evidence-based early intervention services have been shown to reduce the core symptoms of autism; improve IQ and daily functioning; and reduce the cost of lifelong care by two-thirds. Considering the cost of autism over the lifespan is estimated at $2.3 million, those are significant savings.

This is just one example of a pressing need related to autism. In fact, the funding that has been provided through this subcommittee is just one piece of the puzzle. Autism Speaks and the three million plus members of our community here in the United States are of course grateful for this funding. It is making a difference. But while we know more than we did a decade ago, there is still so much more to discover. Why are boys four to five times more likely to have autism than girls? What accounts for the differences between those who are eventually able to live independently versus those who will require lifelong assistance?

As I hear from the families struggling to find and to pay for the appropriate services and treatments for their children; struggling to address the hazards of wandering; and struggling to find housing and jobs for the fast growing population of adults with autism; I know there is so much more to do as well.

We need leadership now more than ever. We need to start looking not just at the cost of what we are doing, but also the cost of not doing more. Thank you for the work you have done so far and I hope we can count on you to make a difference.

Mr. STEWART. Thank you, Ms. Fields, for your concise testimony. Thank you.

The chair now recognizes Dr. James Fortenberry, pediatrician in chief at Children's Healthcare of Atlanta.

TUESDAY, MARCH 25, 2014.

CHILDREN'S HEALTHCARE OF ATLANTA

WITNESS

JAMES FORTENBERRY, PEDIATRICIAN IN CHIEF, CHILDREN'S HEALTHCARE OF ATLANTA

Dr. FORTENBERRY. Thank you.

Chairman Kingston, members of the subcommittee, thank you for the opportunity to testify in support of the Children's Hospitals Graduate Medical Education program, or CHGME.

I am Dr. Jim Fortenberry. I am pediatrician in chief at Children's Healthcare of Atlanta, and I am also a pediatric intensive care specialist there.

On behalf of Children's and also the Children's Hospital Association, I first want to thank the chair and the committee for the ongoing support that you have given to the CHGME program.

CHGME supports children's health by providing independent children's hospitals with support for graduate medical education to train future young physicians in pediatrics and pediatric specialties. It is comparable to the funding previously that adult hospitals receive through Medicare.

Since the program's beginning, CHGME has enjoyed strong bipartisan support in Congress under both Republican and Democratic leadership, and for that we are tremendously grateful.

CHGME funding has had a tremendous positive impact. It has enabled children's hospitals to increase their overall training by more than 45 percent since the program began in 1999. In addition, the CHGME program has accounted for more than 74 percent of the growth in the number of new pediatric subspecialist positions being trained nationwide.

Today, the 55 hospitals that receive CHGME train over 6,000 residents annually. This equates to training about half of all pediatric residents in the country, including 45 percent of general pediatricians, 51 percent of pediatric specialists. And that includes specialists in the States of Arkansas, Georgia, Alabama, Connecticut, Utah, California, Ohio, all the States represented by the committee members.

However, in 2012, the Children's Hospital Association conducted a survey that found that children's hospitals across the country continue to experience significant shortages in some pediatric specialties, in particular pediatric neurology, pediatric endocrinology or the care of children with diabetes, pediatric—developmental pediatricians that take care of children with autism.

The pediatric specialty shortages that we see affect children's and their families' ability to receive timely care, appropriate care, and necessary procedures, surgery, assessment for development. The wait time for these specialties far exceeds the national averages, sometimes taking months to see a pediatric neurologist, for

instance, in Georgia, where we are experiencing significant shortages in neurologists.

The White House's fiscal year 2015 budget proposes eliminating funding for CHGME and incorporating support for training into a new competitive grant program under HRSA, with a minimum of $100,000,000 set-aside specifically for children's hospitals. This is compared to the current $265,000,000 support that the committee has supported.

While the White House specifically includes funding for training in children's hospitals in the budget, the administration's proposal unfortunately continues to underfund pediatric training in this model. Furthermore, children's hospitals have strong concerns that replacing the current system with competitive grants that are limited in duration and available only to a much smaller group of institutional recipients puts at risk the gains that have been made for children's health under CHGME across the country.

We welcome the idea to try to engage with administration and Congress on ways to strengthen the pediatric workforce. However, in the present, financial support for GME really needs to be uninterrupted and undiminished to continue to build on these gains.

We are so grateful to House and Senate lawmakers for reaffirming the bipartisan support that you provided in providing $265,000,000 for CHGME in fiscal year 2014. In 2015, on behalf of CHA and Children's Healthcare of Atlanta, I respectfully request that Congress provide $300,000,000 for CHGME funding and in an uninterrupted, noncompetitive grant fashion.

We recognize that the fiscal climate is extraordinarily challenging and that Congress has a responsibility to carefully consider the Nation's spending priorities. However, the CHGME program is critical to protecting gains in pediatric health and ensuring access.

Again, on behalf of Children's and CHA, thank you for your past support. I ask that you would provide continued support for CHGME program in an uninterrupted fashion so that we can continue to train the next generation of general and specialized pediatricians for our children and for our grandchildren.

Thank you.

[The information follows:]

House Labor HHS Subcommittee Testimony
Dr. James Fortenberry, Pediatrician in Chief
Short Oral Testimony/Talking Points

Chairman Kingston, Ranking Member DeLauro and Members of the Subcommittee, thank you for the opportunity to testify in support of the Children's Hospitals Graduate Medical Education program, or "CHGME".

I am Dr. James Fortenberry, Pediatrician in Chief for Children's Healthcare of Atlanta. On behalf of Children's Healthcare of Atlanta and the Children's Hospital Association, I would like to thank the Chairman and the Committee for the ongoing support you have given to the CHGME program.

CHGME supports children's health by providing independent children's hospitals with support for graduate medical education comparable to funding that adult teaching hospitals receive through Medicare. Since the program's beginning, CHGME has enjoyed strong, bipartisan support in Congress, under both Republican and Democratic leadership. Children's hospitals are extremely grateful to Congress and the members of the Subcommittee for their outstanding history of supporting CHGME.

CHGME funding has had a tremendous impact, enabling children's hospitals to increase their overall training by more than 45 percent since the program began in 1999. In addition, the CHGME program has accounted for more than 74 percent of the growth in the number of new pediatric subspecialists being trained nationwide.[1] Today, the 55 hospitals that receive CHGME, less than one percent of all hospitals, train over 6,000 residents annually. This equates to the training of 49 percent of all pediatric residents in the country, including 45 percent of general pediatricians and 51 percent of pediatric specialists.

In 2012, the Children's Hospital Association conducted a survey that found Children's hospitals across the country continue to experience significant shortages in some pediatric specialties.
The pediatric specialty shortages affect children and their family's ability to receive timely, appropriate care, including surgery. Children's hospitals clinic wait times are on average two weeks; but for certain pediatric specialties experiencing

[1] Received by Kris Rogers, Director of Clinical Research at CHOA, stating this is a statistic from the American Medical Association.

physician shortages, the wait time far exceeds this standard up to 14.5 weeks and beyond.

The White House's FY 2015 budget proposes eliminating funding for CHGME and incorporating support for training at children's hospitals into a new competitive grant program under HRSA, funded from Medicare trust fund dollars. A minimum of $100 million would be set aside specifically for children's hospitals in FY 2015 and FY 2016.

> While the White House specifically includes funding for training in children's hospitals in the budget, the administration's proposal continues to underfund pediatric training. Furthermore, children's hospitals have strong concerns that replacing the current system with competitive grants that are limited in duration and available only to a limited class of recipients puts at risk the gains that have been made for children's health under CHGME.
>
> Children's hospitals welcome the idea of engaging with the administration and congress on ways to strengthen the pediatric workforce for the future. In the present, however, financial support for GME in children's hospitals needs to be uninterrupted and undiminished. Proposing to eliminate support for a current program with a proven track record of success

Children's hospitals are grateful to House and Senate lawmakers for reaffirming bipartisan support for CHGME and for providing $265 million for CHGME for FY 2014, essentially level funding over 2013.

For FY 2015, [on behalf of [CHA and Children's Healthcare of Atlanta] I respectfully request that Congress provide $300 million for CHGME. We believe that funding in this amount is justified based on continuing pediatric workforce needs, particularly in the area of pediatric sub-specialties, where many shortages still exist. We recognize that the fiscal climate is extraordinarily challenging and that Congress has a responsibility to carefully consider the nation's spending priorities. However, the CHGME program is critical to protecting gains in pediatric health and ensuring access to care for children nationwide.

On behalf of Children's Healthcare of Atlanta and the Children's Hospital Association, and the children and families we serve, thank you for your past support for this critical program and your leadership in protecting children's health. I strongly urge continued support for the CHGME program in FY 2015 so that we may continue to train the next generation of general and specialized pediatricians.

Again, thank you for this opportunity to testify before you today and I welcome any questions.

Mr. STEWART. Thank you, Doctor.

And the chair recognizes the chairman of the subcommittee.

Mr. KINGSTON. Dr. Fortenberry, thank you very much, and please give Donna Hyland and Ron Frieson my best. And I really appreciate everything that you do, not just for the children of Georgia, but for the children of America and the southeast.

And I want to say to my subcommittee members, if you are ever in Atlanta and want to have a great tour, you should take the time, and one of the things we often emphasize on this committee is you really need to tour a children's hospital, particularly the emergency room or where the operations are, because you will realize why their expenses are different and their needs are different than a regular hospital.

And I know the members of this subcommittee are very sensitive to that, but I think that a tour sells your case like nothing else. I don't know if any committee members have any comments on that. But——

Dr. FORTENBERRY. The invitation is open. I will leave my card and cell number. We would love to have you along. I am sure the nurses would appreciate your help. It gets a little hectic in the EDs, and we need all the help we can get.

Ms. LEE. Well, Mr. Chairman, let me—can I just comment? I agree, and I would like to visit the Atlanta Children's Hospital.

In Oakland, we have, of course, a children's hospital which is also phenomenal. I work with them very closely. And in fact, when my children were children, I spent many a night and many a day in children's hospitals, and I can attest to the fact that we need more. We need more pediatric healthcare professionals, and we need more funding for children's hospitals.

Dr. FORTENBERRY. Thank you.

Every State has a gem of a children's hospital, and this program has helped bring that training out into all those States. We found that trainees, the State they are trained in, they tend to stay there. So that helps provide that access that we need in every State of the union. And this program has been incredibly valuable in helping that happen.

Mr. STEWART. Thank you, Doctor.

And as with Ms. Lee, having had two of my children under the intensive care of a neonatologist, we appreciate what you do.

And Mr. Kingston, I have a deal for you. I will go tour Atlanta if you will come to Utah and tour our facility there as well.

Mr. KINGSTON. We will call it a day. We will figure it out. [Laughter.]

Ms. Lee and I will come. I would love to do it.

Mr. STEWART. Thank you, Doctor.

We are going to rearrange the schedule just a little now. We invite Samir Khleif, Director of Cancer Center at Georgia Regents University to join us now.

TUESDAY, MARCH 25, 2014.

GEORGIA REGENTS UNIVERSITY

WITNESS

SAMIR N. KHLEIF, M.D., DIRECTOR, CANCER CENTER, GEORGIA REGENTS UNIVERSITY

Dr. KHLEIF. Thank you. Thank you.

And may I invite you also all to come to the Cancer Center in Augusta. Particularly, we have the Masters now. It might be a good thing to do.

Mr. KINGSTON. For the record, I want to clarify that. You are saying Masters tickets come with the tour? [Laughter.]

Dr. KHLEIF. That would be——

Mr. STEWART. And with that, Doctor, we will release you.

Dr. KHLEIF. So, Mr. Kingston, Mr. Chairman, as a Georgian, I must say we are really very proud that you are chairman of this very important committee, and I really would like to thank you, first, for having me here to testify and, second, for all your support for the health of Georgians, for biomedical research, and for NIH. So thank you very much.

Biomedical research has clearly made amazing impact and great strides on the health of our Nation, and to a large degree, this is because of NIH and NIH funding. Also, good part of the century, we in the U.S. have been the beacon for biomedical research and the translation of this biomedical research into better life, better health, and better quality, and we led the world in this.

And I must say also the credit should go to a large degree to the unmatched NIH funding. And for that, we should not falter.

Also, I must also say that we have maintained through the years an edge over the rest of the world in our health science research and our discovery and innovation and also affected our economy, and for that, I would say that edge must not be lost.

Mr. Chairman, this is why it is extremely important to actually say that we should maintain or increase the NIH funding up to $32,000,000,000, including National Cancer Institute up to $5,000,000,000. That would give us the tools to maintain the progress to cure diseases, improve lives, and keep us at our advantage in the whole, entire world.

Now we have been successful on certain areas, but I really believe that my view that we fell short on issues relevant to other areas like health disparity. And this is where burden-relevant funding would be of high value.

Let me give you a few examples from the State where I come from. If you are an African American in the State of Georgia, you have possibility twice to have prostate cancer than if you are white and three times more to die from prostate cancer than if you are white.

If you are an African-American woman, you will die one-third, 30 percent more than if you are a white woman and same thing for colon cancer, 40 to 50 percent more death if you are an African American than if you are white.

You know, to be a stronger nation, we have to address some of these specific issues relevant to health for underprivileged commu-

nities and minorities. And that includes a few other things that I might suggest.

One, we absolutely need to develop more programs to enhance participation of minorities in clinical trials. You know, I would you in cancer, 5 percent of the participants in clinical trials are African American only. And that, of course, leads to less proper scientific conclusions and effective drugs and agents for these kind of populations.

Second, we have to make more effort in developing program that understand the biology of the diseases in these populations, in minorities and underprivileged populations, for example in cancer.

And third, we have to try to understand and correct the reasons for high-risk behaviors in certain population and to design and execute better prevention programs and fund those kind of programs and studies. And actually, this can also allow us to make more progress with less dollars.

We at the Georgia Regents University and GRU Cancer Center, we are making major investment in development of Cancer Center—to address the burden of cancer in minorities. As a matter of fact, that included clinical trial operation that has high minority groups, include the development of a State tumor biobank that would allow us to study cancer in African American in particular, particularly in our States, and also programs to address the risk behavior such as smoking, human papillomavirus, or obesity, three of the major factors that lead to high level risks in the State, particularly in African American.

We believe that these are very important issues that would pave the way for a better future and stronger nation for us.

Mr. Chairman, I thank you again for your support, and I hope not only you would come back again to Augusta, but everyone of this membership will come visit us in Augusta.

[The information follows:]

Congressional Testimony for Public Witness Hearing

Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Tuesday March 25, 2014

Statement of Dr. Samir N. Khleif, M.D.
Director, Georgia Regents University Cancer Center and Cancer Service Line
Professor of Medicine and Biochemistry & Cancer Biology

Introduction

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to speak with you today about the need for funding the National Institutes of Health at a level of $32 billion for Fiscal Year 2015. My name is Dr. Samir Khleif, and I am the Director of the Georgia Regents University (GRU) Cancer Center in Augusta, Georgia. Founded in 1828, GRU is one of four comprehensive research universities in Georgia and home to the state's only public academic health center and sixth largest public medical school in the country. I am here today to discuss the importance of increased NIH funding for cancer research and the need for more funding devoted to the elimination of cancer health disparities, particularly among minority and economically disadvantaged populations.

NIH Funding

America's biomedical research infrastructure has positively impacted health outcomes, created jobs, and spurred economic growth across the United States. Research at the National Institutes of Health, and the National Cancer Institute in particular, has transformed the way cancer is prevented, detected, and treated. Nonetheless, the burden of cancer continues to rise. Nearly every American family has been impacted—or soon will be—by a loved one's cancer diagnosis.

By 2030 the number of new cancer cases in the U.S. will have risen 45% over 2010, with the increase driven by cancer diagnoses in older adults and minorities. Greater investment in biomedical research, particularly cancer research, is critical. Unfortunately, in recent years NIH funding levels have not kept pace with growing needs.

In fiscal year 2013, NIH endured a loss of $1.5 billion in federal funding; as a result, hundreds of high potential biomedical research projects across the country went unfunded. According to the NIH, 640 fewer competitive research project grants were awarded as a result of budget cuts and NIH was able to fund just one out of every six grant proposals. NIH grants drive our country's biomedical research innovation. Findings from these grants fuel our innovation economy, leading to the development of intellectual property and the investment of tens of billions of dollars each year by companies working to transform these discoveries into new medicines. Due to decades of sustained strong investment in NIH and NCI, remarkable progress is being made in cancer research and treatment, including in just the past 18 months: 13 new drugs for treating a variety of cancers; 6 new uses for previously approved drugs; 3 new imaging technologies; and the first high throughput sequencing machine, which will help tailor treatments for cancer patients. I join the biomedical research community in urging the Committee to increase the NIH funding level to $32 billion in fiscal year 2015 and keep our best and brightest minds focused on developing the biomedical research breakthroughs that save lives.

GRU Cancer Center Mission

Through funding from the NIH, as well as other public and private sources, the GRU Cancer Center is focused on reducing the burden of cancer in the State of Georgia. We pride ourselves in offering our patients access to a broad range of cutting edge clinical trials, including several

first in human and first in the nation treatment protocols. We are home to one of the best and most cohesive immunotherapy research programs in the United States with real world "bench to bedside" state of the art immunotherapy treatments for patients. We have the only NCI Minority-Based Community Clinical Oncology Program in the state. And as Georgia's only publically funded cancer center, we are focusing on the populations around us most in need of additional research and outreach.

The Burden of Cancer in Georgia

I would like to provide you with a brief snapshot of cancer in Georgia, currently the 8th most populous state in the nation:

- This year, over 47,000 Georgians will be diagnosed with cancer and more than 16,000 Georgians will die from cancer;
- Georgia ranks 8th in the nation for breast cancer mortality and 10th in the number of new prostate cancer cases per capita;
- It is projected that in 2020 cancer-related medical costs for Georgia will be $7.3 billion.

When it comes to cancer disparities in Georgia, the picture is even more alarming:

- African American women in Georgia are 25% more likely to die from breast cancer than Caucasian women;
- African American patients with colorectal cancer are 45% more likely to die of their disease than Caucasian patients;
- And, not only do African American males in Georgia have the 5th highest incidence rate for prostate cancer among African American males nationally, these men are twice as

likely to be diagnosed with prostate cancer as Caucasian males in Georgia and nearly three times as likely to die from their disease!

There are many potential reasons for these and other cancer health disparities between African American and Caucasian populations in Georgia, including lack of health insurance, low socio-economic status, lack of convenient access to health care, cultural differences in care seeking behaviors, genetic factors, and greater risk factors, such as smoking, obesity and excessive alcohol intake among certain populations. More research is needed to fully understand which of these factors, and possibly others, are the main contributors to disparities, which are most amenable to intervention, and what types of interventions are most effective.

Cancer Disparities

One key to eliminating health disparities is ensuring the tools we use to fight cancer actually work across diverse populations. African Americans and other minority groups have disproportionately high cancer rates, but their enrollment in clinical trials remains disproportionately low. A major study published just last week found that Hispanics and Blacks have a participation rate of just 1.3% in cancer clinical trials. And, out of about 10,000 NIH clinical trials counted, only 150 focused on a particular ethnic or minority population. As noted by the study's leader, "The proportion of minorities in clinical research remains very low and is not representative of the U.S. population with cancer. What is needed is a deliberate effort. Minorities are not hard to reach. They are hardly reached." (1) Without more diverse participation, it is nearly impossible to determine whether new cancer therapies will be safe or effective for patient groups that are not well represented in the clinical trial population. While

we as an institution seek to find cures and effective treatments for cancer, these data are essential if we are to eliminate disparities.

GRU Cancer Center provides care to a large population of African American patients. By making it a priority to enroll all eligible patients into clinical trials, we have been very successful in securing high African American enrollment in these critically important studies of new cancer treatments. Over the past ten years, the annual percentage of African American and other minority patients we have enrolled in NCI-sponsored cooperative group trials has ranged from 34 to 57%. Increasing minority participation in clinical trials to at least the level they are represented in the population must be a priority for the NIH if we are to achieve our goal as a nation to reduce cancer morbidity and mortality.

Closing

Mr. Chairman, thank you for your support and interest in cancer health disparities. I appreciate you taking the time to come to the Cancer Center to meet with me and my researchers to better understand the service and care we provide for citizens of Georgia and others around the world. To the rest of the committee members, I would like to extend an open invitation to visit our campus in the future. I thank you very much for your longstanding bipartisan support of NIH and for providing me the opportunity to speak today. Expanding the NIH budget is imperative if we are to continue making cancer research and biomedical science a national priority. I am available to answer any questions for you now or in the future for the record.

(1) University of California, Davis Comprehensive Cancer Center, news release March 18, 2014

Mr. STEWART. Thank you, Dr. Khleif.

Mr. Kingston.

Mr. KINGSTON. Thank you, Mr. Chairman.

Dr. Khleif, it is another great tour that I would recommend, and I wanted to underscore something that you said. And I want my friend Ms. Lee, I wanted to mention to you that we had worked with Greg Meeks and I talked also to Marcia Fudge about the trial, clinical trials and increasing African-American participation in it.

And actually, there is a group in California that is doing this and outreach. And it is a nonprofit organization that does help supplement the cost to participate in the clinical trials for people. And what we believe is very, very important is to get the participation up so that we can learn more about the science.

And we are excited that this subcommittee, with your support, has put in some language to encourage more participation from minority groups into clinical trials. But to my knowledge, this is maybe the first time anybody has brought it up in a testimony. But it is unbelievable that the cost of participating in a clinical trial over a 10-year period of time often keeps certain people from being able to do it.

And I know in one case, they were telling me in California that people who were in L.A. had to drive to San Francisco once a week to see a physician, take time out from their work. They couldn't drive. They had to have somebody drive them. They had to spend the night in a hotel.

And so, it wasn't that they weren't willing. It is just that the plain old logistics and affordability kept a lot of people out of it.

Dr. KHLEIF. Correct. Access is part of that. Absolutely.

Ms. LEE. Yes. And thank you for raising this and for your support.

This has been an historical issue in communities of color in terms of the participation in clinical trials. So, finally, we are beginning to see the light.

And also, yes, we very seldom hear witnesses testify with regard to health disparities, and I am very delighted that you raised this because we have allocations we have to look at. And some of us continue to fight to increase funding for all of the efforts around health disparities and beginning to help us close the health disparities.

The Black, Latino, and Asian Pacific American Caucus, every year, we fight for this. We fought for this in the Affordable Care Act.

But also at this subcommittee, we want to make sure that all of the institutes for minority health and all of the research and all of the programs that begin to address what you are explaining to the subcommittee are really funded at the levels that would really make an impact.

So thank you very much.

Dr. KHLEIF. That would be very important.

Mr. KINGSTON. And we are also working on a resolution within NIH about this to get the participation up on a broader spectrum of the representative samples of the population.

So thanks.

Dr. KHLEIF. Thank you.

Mr. STEWART. All right. Thank you, Dr. Khleif.

We look forward to those Augusta tickets. [Laughter.]

Mr. KINGSTON. Mr. Chairman, I noticed that the folks from Hope are next. Is that——

Mr. STEWART. Yes, that is right. Reaching for the Stars.

Mr. KINGSTON. And you had some people out in the hall. Can we get them in? If you guys maybe—I would like them to come in. We will be happy to move some chairs if this is helpful, or whatever we need to do to make that happen.

[Pause.]

Mr. STEWART. We invite Cynthia Frisina then, the executive director, Reaching for the Stars. A Foundation of Hope for Children with Cerebral Palsy.

And thank you for joining us.

Ms. FRISINA. Thank you.

Mr. STEWART. And we should note she is accompanied by Dr. Lisa Thornton as well.

TUESDAY, MARCH 25, 2014.

REACHING FOR THE STARS. A FOUNDATION OF HOPE FOR CHILDREN WITH CEREBRAL PALSY

WITNESSES

CYNTHIA FRISINA, EXECUTIVE DIRECTOR, REACHING FOR THE STARS. A FOUNDATION OF HOPE FOR CHILDREN WITH CEREBRAL PALSY

DR. LISA THORNTON

Ms. FRISINA. Thank you very much. Thank you, Mr. Chairman. Thank you, members of the committee.

It is an honor to be here today, particularly because it is National Cerebral Palsy Awareness Day, coincidentally. And we are very glad to be here speaking on behalf of the 800,000 Americans and more than 17 million people worldwide with cerebral palsy.

I am Cynthia Frisina. I am the mother of a daughter with cerebral palsy and head of Reaching for the Stars, the largest nonprofit foundation in the world, actually, led by parent volunteers. With me is Dr. Lisa Thornton, who is also on the executive board of the American Academy for Cerebral Palsy and Developmental Medicine.

Today, we are here to ask Congress to help us. What we are asking is to take all steps necessary to establish a two-prong cerebral palsy research initiative, specifically allocating $10,000,000 in dedicated funding to the CDC to conduct research into the causation and prevalence of cerebral palsy, leveraging the existing infrastructure that already exists. And $30,000,000 for high-priority NIH funding for translational CP research.

CP, which is what cerebral palsy is called, is the most common motor disability in children, affecting 1 in 323. Ten thousand babies every year are born with cerebral palsy, and there is no known cure right now, and no cause has been researched. We find this quite astounding.

Some children with CP can walk, and people with CP. But others, and you see many of them in this room right now, are trapped

in bodies that don't work correctly. They can't talk, and there is not the research being done right now to help them.

The reason I am here started 13 years ago when my daughter was born 3 months prematurely. She was in the NICU for 4 weeks. We hoped that she was going to be okay. She fought for life. We thought we were out of the woods, and then we got the diagnosis for CP. We didn't even really know what that was at the time.

And when you get a diagnosis like that, that is so devastating, where you don't know—you know your child is going to be faced with surgeries, painful everyday tasks are so difficult, it is really heartbreaking. We could not, at her diagnosis, even get answers to the simplest question of whether or not she would walk or talk.

Her care cost over $100,000. When she was discharged, she was discharged with no treatment plan, no care plan. It is still the same today. Unfortunately, our situation is all too common.

So we decided to do something about it. We formed our foundation, which is now the largest in the world, and we have families all over looking for answers.

Cerebral palsy currently does not have any standard protocol. There is no treatment plan. There has been no talk of recovery until just recently, and there is no current cure.

Dr. THORNTON. Despite the number of Americans impacted by cerebral palsy, there is zero dedicated public research funding for it at NIH or CDC. There is no Federal strategy to address this, the number-one motor disability of children, affecting a large adult population as well.

We ask you to contrast this with the NIH research funding for adult stroke with that with cerebral palsy. There are about 800,000 new adult stroke cases every year. In 2013, stroke received $282,000,000 in NIH research funding, equating close to $24,000 per adult stroke case.

In contrast, more than 10,000 babies each year are diagnosed with CP. Eighteen million dollars in NIH grant initiated CP research in 2013 equates to less than $1,800 per new baby diagnosed. CP received less than 1/10th the funding of adult stroke, even though most children with CP are expected to live a normal life expectancy.

It is illogical to think that injured brains can improve, but baby brains cannot. Lifetime care and medical costs for all Americans with CP exceeds $1,500,000 per person over someone who does not have CP. And indeed, lifetime care costs for all babies born with CP in just the year 2000 will total over $11,500,000,000.

Investing in CP research funding with the goal of preventing and minimizing the impact of CP would dramatically reduce these staggering costs and the cost of human suffering.

Ms. FRISINA. Two weeks ago, we launched a national petition. As of this morning, we have over 5,000 American signatures in less than 2 weeks about how important this issue is. We really appreciate the committee's support for the CDC and everything you have already done for birth defects and developmental disabilities, as well as the NIH, especially your upcoming BRAIN initiative as well. We hope that includes the brains of people with CP.

And we thank you very much and hope that you will help us.

[The information follows:]

Chairman Kingston, and Distinguished Members of the Committee:

Thank you for allowing us to speak on *National Cerebral Palsy Awareness Day* on behalf of the more than 800,000 Americans and 17,000,000 people worldwide with Cerebral Palsy. My name is Cynthia Frisina and I am the mother of a daughter with Cerebral Palsy. I am also the Executive Director of *"Reaching for the Stars. A Foundation of Hope for Children with Cerebral Palsy"*, the largest pediatric Cerebral Palsy nonprofit foundation in the world led by parent volunteers. With me is Dr. Lisa Thornton, Executive Board member of *"Reaching for the Stars"* and the *American Academy for Cerebral Palsy and Developmental Medicine.*

Today we ask Congress to take all steps necessary to establish a two-prong National Cerebral Palsy Research Initiative.

1. Allocate $10 million in dedicated federal funding for CDC to conduct research into the causation and prevalence of Cerebral Palsy leveraging existing research infrastructure.
2. Allocate $30MM for high priority NIH funding for translational CP research.

Cerebral Palsy (CP), the most common motor disability in childhood, is a devastating group of disorders, disrupting a person's ability to move, sit, stand, walk, talk and use their hands. CP is caused by a non-progressive injury to the developing brain and the severity can vary: Some patients have only mild difficulties with balance, walking and fine motor skills, while others are completely trapped in their own bodies, fighting rigid limbs, and unable to speak or swallow. *75% of people with CP have additional conditions*, including epilepsy, autism, hearing and vision impairments, communication problems, and chronic pain. More than 10,000 babies are diagnosed with Cerebral Palsy each year. In most cases, the specific cause is unknown. There is currently no known cure.

The reason I am here today began 13 years ago when my daughter, Cathryn was born three months early, weighing 3 pounds and fighting for life. After a month-long stay in the NICU, we hoped she was out of the woods, but I knew something was wrong. Cathryn wasn't hitting basic milestones. She was floppy, then stiff, and held her head to one side. She choked when drinking and fisted her hands oddly. When a neurologist finally diagnosed Cathryn with CP at 11 months of age, we had no answers to even the simplest questions of whether she would be able to walk or talk. We were told to wait and hope for the best. *Like the majority of others who receive a CP diagnosis, the cause of Cathryn's Cerebral Palsy remains unknown.*

Cathryn's care in the *Neonatal Intensive Care Unit* (NICU) cost well over $100,000, yet post discharge, there was no treatment protocol or plan to help her reach her potential. Unfortunately, our experience is still all too common, and typical NICU costs are even higher today.

After an exhausting search for answers and finding very little regarding early treatments for children with CP, we launched *Reaching for the Stars* in 2005 - the first parent-led voice of children with Cerebral Palsy focusing on advocacy, research and education. Thousands of families across the U.S. and into Canada, Australia and Asia are part of our growing CP community. We have an outstanding international Medical Advisory Board to advise us.

Over the years, our treatment search has taken us all over the country with no two opinions the same regarding surgeries, medications, devices, various therapies etc. Cathryn's story highlights the current reality that there is <u>no consensus of "Best Practices" for a person with CP – at diagnosis, or through their life span. Cerebral Palsy does not have organized standards of care or proven therapy protocols. Until just recently, there has been little talk of recovery, let alone a cure for CP.</u>

Despite the number of Americans impacted by Cerebral Palsy, there is ZERO dedicated public research funding for it at NIH or CDC. There is no federal strategy to address the #1 motor disability in children - affecting a large adult population as well. We ask you to contrast the NIH research funding for Adult Stroke with that of Cerebral Palsy. There are approximately 795,000 new Adult Stroke cases each year. In 2013, Stroke received $282,000,000 in NIH research funding - *equating close to* $24,000 per new adult stroke case. In contrast, more than 10,000 babies each year are diagnosed with CP. $18,000,000 in NIH grant-initiated CP research in 2013 *equates to less than $1,800 per new baby diagnosed.* This was less than one tenth the funding for Adult Stroke, even though most children with CP are expected to live a normal lifespan.

Human brain neuroplasticity is now an accepted scientific fact that has revolutionized the care of adults with a wide variety of brain injuries and diseases. If we compare the care of an adult with a stroke involving one side of the body, to a child with hemiplegic Cerebral Palsy involving one side of the body, there is a world of difference in the available treatments and hope for recovery. *It is illogical to think that older injured brains can improve, but baby brains cannot.*

It is estimated that lifetime care and medical costs for all Americans with CP exceeds $1.5MM per person more than someone who does not have CP causing financial devastation in the struggle to afford care and treatment not covered by insurance. Government programs, like Medicaid, bear much of this cost. **Lifetime care costs for those born with CP in 2000 will total over $11.5 billion.** Investing in CP research funding, with the goal of preventing and minimizing the impact of CP, would dramatically reduce the staggering costs and human suffering. In the

age of human neuroplasticity, *continuing the status quo is no longer an acceptable course of action.*

Mr. Chairman, thank you and the Subcommittee, for your leadership in supporting the CDC's research into birth defects and developmental disabilities, which includes local surveillance of CP in four sites as part of the *ADDM Network.* We also thank the committee for your ongoing support of NIH research into brain development and injury, including the new *Brain Initiative,* and hope it will include the brains of people with Cerebral Palsy as well.

Thirteen years after Cathryn was discharged from the NICU babies with brain injuries in most cases, are shockingly STILL being discharged with little more than a *"wait and see"* attitude - despite recognition of the importance of the first few years of every baby's life when the brain grows rapidly with exuberant neuroplasticity and realistic hope for significant recovery. Children like Cathryn lose valuable therapeutic time with the usual delay in CP diagnosis. Many children are not diagnosed until age 2 or 3, or even later. Knowing what we now know about neuroplasticity, it is tragic there is not an aggressive protocol in place from the minute a brain injury in a baby or toddler is suspected. There should be.

The wonderful research focused on adult brain disorders is not being effectively translated to benefit the most precious resource we have - our children. There is incredible financial and societal cost that could be saved by shifting our approach to cross-disciplinary translational CP research. There are many research areas where we don't need to "rediscover the wheel". One example is *Constraint Induced Movement Therapy* (CIMT) introduced and tested successfully in adults with stroke over 30 years ago, and proven to be successful in children as well. This is just one treatment modality that works in both children and adults, yet there is no widespread use or availability of it to U.S. children with CP. Further research is needed to determine which treat-

ments, or combination of treatments, offer the best hope for improvement and recovery, and to translate treatments and technologies known to work for adult brains to children with CP.

Two weeks ago, *Reaching for* the *Stars* launched a *national petition to regarding the need for federally funded Cerebral Palsy research.* http://www.change.org/petitions/us-senate-and-us-house-of-representatives-appropriate-dedicated-funding-for-cerebral-palsy-prevention-treatment-and-cure-research In that short amount of time, *5,000 Americans have signed this petition*! Our community is coming together because it is incomprehensible that so many basic questions have not been answered about a disorder that impairs movement in more children than any other.

There are many examples of what can happen when government resources and ingenuity meet: sending a man to the moon, changing HIV from a death sentence to managed chronic disease. People with Cerebral Palsy deserve nothing less than our best efforts.

Mr. Chairman and members of the Subcommittee, we thank you very much for the opportunity to speak to you today, and for your time and attention to this urgent matter. Dr. Thornton and I would be happy to provide any additional information and answer questions.

For more information please visit www.reachingforthestars.org Our mission is the Prevention, Treatment and Cure of Cerebral Palsy.

CDC Disorders	U.S. Population	2013 Budget
Fetal Alcohol Syndrome	0.2 - 1.5 per 1000	$10,168,000
Spina Bifida	1 in 1400	$5,939,000
Autism/ASD	1 in 88 children	$21,665,000
Thallasemia	Less than 1,000 in U.S.	$1,863,000
Cerebral Palsy	1 in 323	$0

An investment of $10MM in CDC's Developmental Disabilities (DD) activities will allow CDC to build on established surveillance and research methods to develop a robust research infrastructure focused on CP across various geographic U.S. regions. Infrastructure of this type holds promise for answering questions about the causes of CP and for identifying opportunities for prevention. The U.S. lags behind other countries like Australia, most of Europe, and the Scandinavian countries in CP research funding translating to improved early diagnosis and care *(Source: Hagberg et al: CP Alliance).*

Mr. STEWART. Thank you, Ms. Frisina, Dr. Thornton.

I am wondering, is your daughter with you today?

Ms. FRISINA. My daughter with CP suffered a concussion from a fall a couple of days ago and couldn't make it. My older daughter, however, is here. She is the redhead.

Mr. STEWART. All right. Well, compelling——

Ms. FRISINA. We have lots of other children.

Mr. STEWART. Yes, you do. Compelling testimony. God bless you all and your organization. So thank you.

Mr. KINGSTON. Do you want to introduce any children?

Ms. FRISINA. Sure. We have Jacob, and we have—he is 4. We have Adriana. We have Laurel. And thank you for allowing us to have them here today.

Mr. STEWART. Yes, thank you.

Ms. FRISINA. I hope that you will take this into consideration.

Mr. STEWART. Beautiful children. Thank you.

All right. We would like to now turn time over to Susan Lavigne, board member, National Senior Corps Association.

TUESDAY, MARCH 25, 2014.

NATIONAL SENIOR CORPS ASSOCIATION

WITNESS

SUSAN LAVIGNE, ATLANTIC CLUSTER REPRESENTATIVE

Ms. LAVIGNE. Good morning. Mr. Chairman, members of the committee, my name is Susan Lavigne, and I am the Director of Senior Volunteer Programs for the Opportunity Alliance in Portland, Maine.

Thank you for the opportunity to speak on behalf of the National Senior Corps Association, representing over 350,000 older Americans volunteering throughout the country.

Senior Corps, administered by the Corporation for National and Community Service, is dedicated to providing older Americans, 55 and over, volunteer opportunities to address critical community needs through three programs—the Foster Grandparent Program, Senior Companion Program, and RSVP, volunteering in schools, child development centers, Head Start, adult day programs, veterans centers, as well as providing home visits to frail elders, helping them to remain living independently.

I appear today to ask you, members of the subcommittee, to reject the President's fiscal year 2015 budget proposal that would reduce and eventually eliminate funding for the Senior Corps. This is not the time, nor will it ever be, to devalue the contributions of the Nation's senior volunteers.

The President's budget poses a threat to the volunteers in all three programs and the communities they serve. If enacted, Senior Corps as we know it will be eliminated. Two-thirds of RSVP programs will be closed, and what will be left will be moved to a smaller component.

Foster Grandparents and Senior Companions would be moved under Americorps, where the new positions would be labeled one-quarter Americorps. It is a label many volunteers have difficulty

with since they no way consider themselves or their efforts as one-quarter.

Foster Grandparents and Senior Companion volunteers live at less than 200 percent of poverty, and they receive a nontaxable stipend of $2.65 an hour. They are not getting paid to volunteer. This token amount ensures it doesn't cost them. The average volunteer in my program actually has income less than 125 percent of poverty.

One needs appropriate clothing and sometimes a vehicle to fulfill their volunteer role. The stipend and other benefits, such as meals and travel, make this possible. The proposal to reduce their ability to earn a stipend beyond $450 is a loss for low-income seniors.

A little about each program. The Foster Grandparent Program has 27,000 participants volunteering 24 million hours a year as tutors and mentors. Teachers report 81 percent of children matched with a foster grandparent improve their academic performance.

In Portland, Maine, 65 percent of students at Riverton Elementary are English language learners. Their teachers report foster grandparents are the reason their students made significant gains in reading because when you have classes with 25 second graders, it is impossible for a teacher to spend individual reading time with each student.

Riverton's grandparents volunteer 5 to 8 hours a day every day, listening to kids read. If they are proficient by third grade, they are more likely to graduate from high school. The President's proposal reduces foster grandparents to just 8.5 hours a week, counter to what we know helps students succeed.

The Senior Companion Program, 13,000 volunteers supporting 60,000 frail and homebound clients. One such client is Julia, who is blind. She was faced with having to leave her home in Rochester, New York, due to her inability to complete the task of daily living. Her family wasn't always able to be with her because of their work schedules.

A senior companion visits in their home, helps with grocery shopping and getting to appointments. Her family tells us she was able to stay at home an additional 5 years because the senior companion was there. Considering that cost of $4,800 for a senior companion, that is quite a savings.

There are thousands of Julias and Julians around the country, with thousands more on our waiting list. They may be forced to leave their home prematurely with the proposed changes.

And then, finally, RSVP, 296,000 volunteers contributing 62 million hours of service nationwide. RSVP is for seniors of all income levels, providing essential services as well as running signature programs, such as Bone Builders, an osteoporosis prevention exercise program so successful a nurse practitioner wrote, "Because of this program, my patients have improved bone density, better balance, stamina, and strength."

The class is a perfect example of prevention at work and exactly the direction the country needs to take. Prevention saves lives, and it saves health dollars. Eliminating two-thirds of the RSVP programs eliminates cost-saving programs such as this.

And finally, Senior Corps is a lifelong for our volunteers. Multiple studies have proven what Fran Seeley, a 73-year-old widow,

says about her quality of life in her 12 years as a foster grandparent.

"Volunteering has given me a reason to get up in the morning. I am needed. I am valued, and I am a contributing member of my community."

Thank you.

[The information follows:]

Testimony Submitted to the House Appropriations Committee Subcommittee on Labor, Health and Human Services, and Education March 25, 2014

Mr. Chairman, Members of the Committee, my name is Susan Lavigne and I am Director of the Senior Volunteer Programs for The Opportunity Alliance in Portland, Maine. Thank you for the opportunity to speak on behalf of the National Senior Corps Association, representing over 350,000 older americans volunteering throughout the country.

SENIOR CORPS, administered by the Corporation for National and Community Service, is dedicated to providing older Americans 55 and over volunteer opportunities to address critical community needs through its three programs -- Foster Grandparent Program, Senior Companion Program and RSVP

Senior Corps volunteers serve in a variety of community settings including schools, child development centers and Head Starts, Adult Day Programs, veteran centers as well as providing home visits to frail elders for companionship and transportation to medical appointments and grocery shopping enabling them to remain living independently.

I appear today to ask that you, as Members of the Subcommittee reject the President's FY 2015 Budget proposal to reduce and eventually eliminate funding for the Senior Corps. This is not the time, nor will it ever be, to devalue the contributions of the nations' senior volunteers, The President's budget poses a threat to the volunteers in all three Senior Corp programs and the communities they serve by eliminating 2/3 of RSVP volunteer programs nationwide and reducing by more than half, the weekly volunteer service by Foster Grandparents and Senior Companions.

If enacted, SENIOR CORPS, as we know it, will be eliminated. Just 1/3 of RSVP will be moved to a smaller component within CNCS and Foster Grandparents and Senior Companions will be moved into AmeriCorps, where their new positions have been characterized as "1/4 AmeriCorps" with a reduction to 450 hours a year--- a term that has offended many of our volunteers who in no way consider their efforts as 1/4.

FGP and SCP are stipended programs, in return for a significant commitment volunteers receive a nontaxable stipend of $2.65 an hour if their income is less than 200% of poverty. They are not getting paid to volunteer, nor are they getting rich, but this token amount insures it does not cost them since the average volunteer in my program has retirement income less than 125% of poverty. One needs

appropriate clothing, and in many cases, a vehicle, to fulfill the important role of mentor, tutor, capacity builder, community liaison. The stipend other benefits such as meals and travel support, make this possible. For many volunteers the proposal will reduce their ability to earn beyond 450 hours, a loss of income for an already vulnerable group.

A little about each program: The Foster Grandparent Program has more than 27,000 volunteers volunteering 24 million hours a year as tutors and mentors for over 232,000 children. Teachers report 81% of children matched WITH a FG improved their academic performance. In Portland, Maine, 65% of students at Riverton Elementary are English language learners. Teachers there report Foster Grandparents are the reason these students made significant gains in reading. When you have classes with 25 second grade students, it is impossible for a teacher to spend individual reading time with each student. Riverton's Grandparents, because they volunteer 5-8 hours a day, every day, are making a difference because they are able to spend time, working with and building relationships with these students on a daily basis, resulting in improving reading skills. As the teachers said: We know that if they are proficient readers by 3rd grade, they are more likely to graduate from high school. The President's proposal reduces Foster Grandparent volunteering to just 8.5 hours a week. Reducing the commitment from an average of 25 hours a week to 8.5 runs counter to what we know helps kids learn -- a consistent, reliable, caring mentor.

The Senior Companion Program has more than 13,600 volunteers supporting over 60,00 frail, homebound clients in needing assistance in order to remain living independently. One such client is Julia, an 80-year old woman, who is blind, and was faced with having to leave her home in Rochester, NY due to her inability to get out and complete the tasks of daily living. Her family wasn't always able to be with her because of their work schedules and own family commitments. Julia was matched with a Senior Companion who helped her with grocery shopping and getting to appointments. Her family tells us she was able to stay living at home an additional 5+ years because of the Senior Companion. Considering the cost of long term care the $4,800 cost for a Senior Companion is quite the savings. There are thousands of Julias, and Julians, around the country, with thousands more on the waiting list, who will be forced to leave their home prematurely if their Senior Companion is no longer available to serve. Now is the time to INCREASE the Senior Companion Program's ability to serve their communities, not decrease.

The RSVP Program has more than 296,000 elderly volunteers contributing 62 million hours of service through 685 projects nationwide. RSVP is a resource for seniors of all income levels who want to volunteer but want a more flexible schedule than FGP or SCP. RSVP's impact is far-reaching -- providing essential client services as well as running local programs such as Bone Builders--an osteoporosis prevention exercise program that is so successful it resulted in this note from a nurse practitioner: My patients have improved bone density scans. They have better balance stamina and strength. They are better informed of their health. The class is a perfect example of prevention at work and exactly the

direction the country needs to take as we tackle the health care crisis. Prevention saves lives and saves health dollars. The proposal eliminates 2/3 of the current volunteers.

And finally, Senior Corps is a lifeline for its volunteers. Multiple studies have proven what Fran Seeley, a 73 year old widow says about her role --- volunteering has given me a reason to get up in the morning, I am needed, I am a contributing member of my community.

Mr. STEWART. Thank you, Ms. Lavigne. We appreciate it.

We would then turn to our next witness, Katie Jones, president of the National Domestic Violence Hotline.

And Ms. Jones.

TUESDAY, MARCH 25, 2014.

NATIONAL DOMESTIC VIOLENCE HOTLINE

WITNESS

KATIE JONES, PRESIDENT, NATIONAL DOMESTIC VIOLENCE HOTLINE

Ms. JONES. Good morning, Mr. Chairman, Representative Lee.

My name is Katie Ray Jones, and I am president and acting CEO of the National Domestic Violence Hotline. We are based in Austin, Texas, and funded on a competitive basis through the Office of Family Violence Prevention and Services at the Department of Health and Human Services.

I want to take a moment to thank you and your staff, who work tirelessly to support the efforts of shelters and the hotline to end violence against women and men and children. Every day, our highly trained advocates answer nearly 700 calls, texts, and chats from those affected by domestic and dating violence. We know that many victims are one call, text, or chat away from serious, if not deadly, violence. It is critical that we are there for them.

Recently, one of our advocates shared a story of a woman who texted the hotline in the middle of the night as her abusive partner slept feet away from her. She shared a story of living in terror every day with not knowing where to go. She felt hopeless and scared. The hotline was able to offer her steps for safety and provide her hope that there was a future that would be violence free.

We know that 1 in 4 women and 1 in 7 men 18 and older in the U.S. have been a victim of severe physical violence by an intimate partner. We know 1 in 3 young people report being abused in their dating relationships. So chances are that you and everyone in this room know someone close to them who is a victim of domestic violence.

The National Domestic Violence Hotline is available for all 24 hours a day, 7 days a week, 365 days a year in over 200 languages. Our teen dating abuse program, Love is Respect, helps millions of young people seeking information about dating abuse and healthy versus unhealthy relationships. They get this information not only through our Web site, but as well as interactive media, text, chat and phone services that are provided by peer advocates.

Over the last 18 years, the hotline has answered for more than 3.4 million victims of domestic violence. Last year, more than 330,000 people sought assistance from us. Almost all of them were experiencing verbal and emotional abuse. Nearly three-quarters were suffering from physical abuse. Many revealed sexual abuse, stalking, child abuse, and economic abuse with over 30,000 needing help with legal issues, such as protective and restraining orders.

The hotline.org and loveisrespect.org receive more than 2.5 million visits in a year. Our expertise is utilized frequently by shel-

ters, community leaders, law enforcement, and even classroom teachers.

Last year, we provided more than 125,000 referrals to domestic violence treatment providers and nearly 40,000 referrals to additional resources across the Nation. But the current economic climate has created a severe budget crisis for our programs that provide safety and support for victims.

A recent survey by the National Alliance to End Sexual Violence revealed that 75 percent of rape crisis centers experienced funding cuts in the past year, leading to long waiting lists for services such as counseling and support groups. A recent census survey by the National Network to End Domestic Violence indicated 66,000 victims received services, but nearly 10,000 requests for services went unmet.

I am sorry. Ten thousand requests for services went unmet due to lack of funding and resources. This means that more and more often, as we try to offer help to victims by referring them to programs in the communities, many programs are no longer open in the evenings or on weekends or open at all.

We work in partnership with local, State, territory, and tribal programs. If any one of us closes or reduces services because of funding shortfalls, everyone is impacted.

So while I am grateful for the opportunity to be with you today to tell you about the wonderful services of the hotline, I am here also to ask you that you make sure that funding for the hotline and the work that we do for victims of domestic violence not only continues, but grows.

We ask today for increased funding for the Family Violence Prevention and Services Act programs. Specifically, for the hotline, we are requesting a funding increase of $5,000,000, up from $4,500,000.

For shelters, we request full funding at $175,000,000 in order to restore the resources and services in communities and save lives. As someone who worked in a local shelter, I know that dollars make a difference, and lives are saved.

I will wrap with this. One of our current individual donors reached out recently to thank us. She contributes monthly to the hotline because when she needed information about her abusive relationship, she turned to us. She got the help she needed to escape her situation and is now proud to call herself a survivor.

It is critical that the hotline is able to pick up the phone, respond to every text message and online chat. People view us a 911 for domestic violence victims. I have included in my written testimony the funding lines that will keep this field strong and able to help victims in the future and request that my written testimony be submitted for the record.

Thank you.

[The information follows:]

Good morning, Chairman Kingston, Ranking Member DeLauro and Subcommittee members.

My name is Katie Ray Jones, and I'm the President and Acting CEO of the National Domestic Violence Hotline. The Hotline is based in Austin, Texas and is funded on a competitive basis through the Office of Family Violence Preventionand Services at the Department of Health and Human Services.

Every day, our highly trained advocates answer nearly 700 calls, texts or chats from those affected by domestic and dating violence. We know that many victims are one call, text or chat away from serious, if not deadly, violence.

Recently, one of our advocates shared with me the story of a young woman who reached out tothe Hotline in the middle of the night. The woman said she was crouching down in a corner of her closet. Her partner was sleeping only feet away.The woman shared that she was crying and shaking, but that she had seen the number to text for help earlier in the day and had saved it. She had finally got the courage to seek help. Thankfully, she got an immediate response. She said shewasn't safe, not even there in her closet, but that this was the only time, place, and way she could reach out for help. The young woman began to share her story and the conversationunfolded. By the end, the young woman heard much needed validation from a knowledgeable and compassionate advocatewho offered steps to safely leave her dangerous situation when the time was right. Most important, she was given hope for a better future.

We know that 1 in 4 women and 1 in 7 men 18 and older in the U.S. have been the victim of severe physical violence by an intimate partner. We know one in three young people report being abused in their dating relationships. So chances are you or someone you know has been affected by domestic or dating abuse.The National Domestic Violence Hotline is the only national resource that takes calls, texts and chats directly from victims and survivors of domestic abuse, their friends, and their families 24 hours a day, 7 days a week, 365 days a year. We have the most comprehensive resource database in the country, with access to more than 4,500 providers and resources across the US, Puerto Rico, the US Virgin Islands and Guam.

Our teen dating abuse program,loveisrespecthelps millions of young people seeking information about dating abuse and healthy vs. unhealthy relationships. They get this information through loveisrespect.org, interactive media, and text, chat and phone services provided by peer advocates. We help victims and their families and friends, whether they

are in the throes of an emergency, seeking local help, or just in need of someone to talk to at that moment. Our expertise is routinely sought by national and regional media, federal, state and local government, service providers, law enforcement and nonprofit colleagues.

Over the last 18 years, the Hotline hasanswered calls from more than 3.4 million victims. In 2013 alone, 331,078 people sought assistance from the Hotline; unfortunately, 77,484 contacts were not answered, due to a lack of resources. Over 6,300 of those who contactedthe Hotline in 2013 were non-English speakers. The Hotline provides bilingual staffing and 24-hour access to interpretersin 200+ languages.

Ninety-five percent of those contacting us disclosed verbal and emotional abuse, while 70 percent reported physical abuse. Eight percent of contacts revealed sexual abuse. Nearly 30,000 victims disclosed legal issues, such as protective/restraining orders (60%), custody and visitation (33%), divorce (20%), and other legal matters. Over 20,000 victims disclosed instances of economic abuse, in which their partner forcibly took control or manipulated their finances in order to wield power over them. Nearly 7,000 victims experienced stalking. Over 5,000 victims disclosed instances of child abuse. Nearly 5,000 victims were struggling with issues related to immigration.

In 2013 alone, our websites were visited a total of 2,151,224 times: 636,404 visited TheHotline.org, and 1,514,820 visited loveisrespect.org for teens and young adults. Our expertise gained from working directly with victims is utilized frequently by shelters, community leaders, law enforcement and even classroom teachers.

The downtrend in the economy has impacted both victims and the local programs that serve them. A third of the victim callers surveyed had experienced a change in their financial situation in the previous year; 98% of those experienced an intensification of abuse during that same period.

But just as victims are reporting increased abuse, programs in the field are struggling. In 2013, the National Domestic Violence Hotline provided 126,305 referrals to domestic violence treatment providers and 36,840 referrals to additional resources across the nation. But thecurrent economic climate has created a severe budget crisis for programs that provide safety and support for victims across the country. A 2013 survey of rape crisis centers by the National Alliance to End Sexual Violence found that over one-third of programs have a waiting list for services such as counseling and support groups, while over half had to lay off staff. The survey found that 75% of rape crisis centers lost funding in the past year through a combination of local, state and federal cuts. Over half of theprograms

experienced a reduction in staffing.

Victims of domestic violence have fewer places to turn, also. According to the National Network to End Domestic Violence's 2013 *Domestic Violence Counts* annual census, in just one day last year, while more than 66,000 victims of domestic violence received services, over 9,640 requests for services went unmet, due to a lack of funding and resources. In 2013, domestic violence programseliminated nearly 1,700 staff positions including counselors, advocate and children's advocate positions. They also had to reduce or completely eliminate over 1,280 services including emergency shelter, legal advocacy, and counseling.

We have seen the impact of these service cuts in our own work. While the Hotline offers important emergency and support services for victims of domestic and dating violence, and for some victims experiencing co-occurring sexual assault and stalking, our goal is to connect these victims with local programs that have the resources to help victims find shelter, transitional housing, legal assistance, and economic supports necessary to help them escape their abusers. Yet, we find, more and more often, as we try to make these referrals, that programs are no longer open in the evenings and on weekends. Other programs have had to lay off bilingual staff, and must call the Hotline to use our language translation services as they are working with victims who have come to their doors.

These local shortfalls of services have additional impacts on the National Domestic Violence Hotline. Because they are so understaffed, three state domestic violence hotlines have approached us to ask if they can roll their hotlines over to us either permanently or during these times of serious funding cuts. The National Domestic Violence Hotline was already unable to answer nearly 80,000 contacts last year due to a lack of resources. If we are not robustly funded through the Department of Health and Human Services and if victim services programs are not vigorously funded through the Family Violence Prevention and Services Act, we will see these unanswered call numbers rise. And even for the calls we are able to answer, the local referrals which these victims' lives depend upon might not be available to help. We work in partnership with local, state, territorial and tribal programs. If any of us closes or reduces services because of funding shortfalls, everyone is impacted.

So while I'm grateful for the opportunity to be with you today to tell you about the wonderful work that the Hotline provides for victims of domestic violence and those close to them, I am also here to ask that you do all you can to make sure that funding for the Hotline and services for the victims of domestic violence continues and grows.

One of our current individual donors reached out recently to thank us. She makes a monthly contribution now to the Hotline. She does this because when she needed information on her abuse, she turned to our website. When her friends and family members didn't know what to doand because her abuser's violence was escalatingshe summoned the courage to call the Hotline. She got the help she needed to escape her situation and is now proud to call herself a survivor. She contributes to the organization because she wants to make sure someone will answer the phone when another victim needs a knowledgeable, compassionate voice. We need more success stories like these.Lives depend on the dedication of our advocates and the reliability of our service.

I have included in my written testimony the funding lines that will keep this field strong and able to help victims in the future.

LHHS Programs

Administration for Children and Families

The National Domestic Violence Hotline – $5 million funding request For the past 15 years the Hotline has provided 24-hour, toll-free and confidential services – immediately connecting callers to local service providers. During this economic downturn, crisis calls to the Hotline have increased.

Family Violence Prevention and Services Act (FVPSA) – $175 million The Family Violence Prevention and Services Act (FVPSA) program is the only federal funding source dedicated to domestic violence shelters and programs, and it supports lifesaving services including emergency shelters, crisis hotlines, counseling and programs for underserved communities throughout the United States and territories.

Centers for Disease Control and Injury Prevention

Rape Prevention and Education (RPE) – $50 million request RPE formula grants, administered by the CDC, provide essential funding to states and territories to support rape prevention and education programs conducted by rape crisis centers, state sexual assault coalitions, and other public and private nonprofit entities. RPE has faced funding decreases since FY '06.

DELTA Prevention Program – $6 million funding request DELTA is one of the only sources of funding for domestic violence prevention work. It supports

statewide projects that integrate primary prevention principles and practices into local coordinated community responses (56 current projects) that address and reduce the incidence of domestic violence

PHSBBG – Preserve Block Grant and include $7 million rape set-aside request The Preventive Health and Health Services Block Grant (PHHSBG) administered by the CDC allows states, territories and tribes to address their own unique public health needs and challenges with innovative and community driven methods. The Public Health Service Act of 2010 included a guaranteed $7 million minimum set-aside to support direct services to victims of sexual assault and to prevent rape. Rape crisis centers depend on this flexible source of funding to provide direct services, operate hotlines and offer prevention programs.

Mr. STEWART. And without objection. Ms. Jones, thank you for what you do. Some of the statistics you shared are startling. One in three, one in four, one in seven.

Thank you for what you do. We appreciate it.

Ms. JONES. Thank you. Thank you for you.

Mr. STEWART. Dr. Lee? And as Dr. Lee comes forward, it is my honor to introduce her. She is actually one of my constituents.

She is an M.D., Ph.D., MBA. She is the dean of the school of medicine, the CEO of the University of Utah Healthcare. You oversee something like a $2,300,000,000 budget. A graduate of Harvard, a Rhodes Scholar at Oxford, more than 150 peer review published publications and recognized by New York magazine as a rising star.

I could go on and on. It is not often that we have such a marginally qualified witness before the committee. [Laughter.]

But we made an exception. I notice you weren't a Girl Scout. I was a little disappointed in that. I know the most important thing I would say about Dr. Lee, she is a wonderful person and a great example of why the University of Utah is recognized as one of the most innovative research centers in the country.

So thank you for being with us. Dr. Lee.

TUESDAY, MARCH 25, 2014.

UNIVERSITY OF UTAH

WITNESS

VIVIAN S. LEE, M.D., PH.D., MBA, UNIVERSITY OF UTAH

Dr. LEE. Thank you so much, Representative Stewart, and nice to see Representative Lee.

Thank you for allowing me to testify.

Today, I would like to talk with you about the future of academic medical centers, transparency and accountability in Government funding, and Angelina Jolie.

Together, we stand at a critical juncture in the history of healthcare, and university hospitals and medical centers like ours at the University of Utah are committed to securing the health of our Nation through high-quality care and effective treatments.

We all know that these are made possible through our diligent investments in research and education. Research and education are critical, and yet the ways in which they are funded are clearly not sustainable.

Historically, clinical revenues have been used to subsidize research and education shortfalls. But now this model is no longer possible as we all try to bend that cost curve. Clinical reimbursement rates continue to fall, challenging us to do more with less. Funding for research and education is at a tipping point.

What are some examples of the cross-subsidization? Well, due to the high cost of biomedical research, academic medical centers now spend an additional 25 to 40 cents for every $1 of external funding received for research.

For education in Utah, our medical school covers the cost of 65 percent of a medical student's education, with only 5 percent fund-

ed by the State and 30 percent from tuition. Once these students graduate and enter residency, academic medical centers still cover more than a quarter of the cost of their training.

At the same time, we serve as the safety net for many low-income and uninsured people, providing over $100,000,000 in charity care this year. It is clear that this model of subsidizing research and education from clinical revenues is not sustainable, and it is not right.

To ensure the kind of transparency and accountability we want in good government, we need to protect and provide the right funding for research to the NIH directly and the right funding for education directly, as in graduate medical education funding and Title VII and VIII programs.

When you make these direct investments, they yield a great return. And an example is the story of Angelina Jolie and the Utah Genome Project. Last year, Angelina Jolie, in an op-ed piece in the New York Times, shared her experience taking steps to reduce her high risk of breast cancer. Her mother had both breast and ovarian cancer, and her maternal grandmother had ovarian cancer, all diagnosed young.

Through genetic testing, Jolie was found to have a mutation in the BRCA1 gene, and she writes about the measures she took to prevent that cancer from afflicting her. Well, what is the Utah connection?

In the early 1990s, after studying numerous Utah families like Jolie's where the mothers and daughters were affected by breast and ovarian cancer, researchers at the University of Utah sequenced the BRCA1 gene and helped to create a test to determine a patient's risk for getting the disease. This discovery has saved thousands of lives around the world.

This University of Utah discovery and our discovery of more than 30 genes, including sudden cardiac death, the APC colon cancer gene, and dozens of other diseases have been made possible through a unique resource called the Utah Population Database, which houses massive family genealogies connected to public health and medical records, by far the largest database of its kind in the world.

Thanks to the foresight of leaders like you and scientific visionaries like Francis Collins, this is just the tip of the iceberg for genomic or personalized medicine. By using this database, the Utah Genome Project is finding those disease-causing genes by comparing the DNA of affected family members with those not affected by disease in areas ranging from autism to Parkinson's disease, from cancer to heart disease.

It is a remarkably powerful tool. And as Congressman Stewart knows well, Utah's large families have given us a great gift, a national treasure.

We respectfully request that your subcommittee fund the NIH at least $32,000,000,000 in fiscal year 2015 to ensure that all of us and our children and their children, like Angelina Jolie, can outlive our family histories.

As we move into an era of personalized medicine, it is also important that we ensure that we have the workforce to care for us and for the next generations. In Utah, Title VII and VIII funding is es-

pecially important. Of Utah's 29 counties, 27 are designed as primary care health professional shortage areas.

And Title VII and VIII programs allow us to address these gaps by funding the training of nurses, physicians assistants, family medicine physicians, and other health professionals so that our communities, both rural and urban, receive the care that they need. And therefore, we urge your subcommittee to provide $520,000,000 for Titles VII and VIII in fiscal year 2015.

In closing, we academic medical centers will work with you to ensure a healthy future for America. To do so, we need to make sure that our funding model is sustainable, transparent, and accountable.

Thank you again for the opportunity to appear before you, and I welcome any questions.

[The information follows:]

Statement by Vivian S. Lee, M.D., Ph.D., M.B.A., Senior Vice President for Health Sciences, Dean of the School of Medicine, and CEO of University of Utah Health Care on FY 2015 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 March 25, 2014

Good morning, Chairman Kingston, Ranking Member DeLauro, Representative Stewart, and distinguished Members of the Subcommittee. Thank you for allowing me to testify. Today I would like to talk with you about the future of academic medical centers, transparency and accountability in government funding, and Angelina Jolie.

Academic Medical Centers: The Future of Health Care

Together we stand at a critical juncture in the history of health care, and University hospitals and medical centers like ours at the University of Utah are committed to securing the health of our nation through the delivery of high quality care and effective treatments. And we all know these are made possible through our diligent investments in research and education. Research and education are critical, and yet the ways in which they are funded are clearly not sustainable. Historically, clinical revenues have been used to subsidize research and education shortfalls. But now, this model is no longer possible, as we all try to bend that cost curve—clinical reimbursement rates continue to fall and uncompensated care costs continue to rise, all challenging us to do more with less. Funding for research and education is at a tipping point.

University of Utah: A Case Study in the Critical Role of Academic Medical Centers

The story of unsustainable cross-subsidization is true for all academic medical centers. In many ways, we at the University of Utah are a typical academic medical center. Like most university health care systems, we offer a continuum of care that is unavailable anywhere else in the community—from population health and wellness to high-end specialty care to serving the

most vulnerable among us. University of Utah Health Sciences is home to vibrant Schools and Colleges of Medicine, Nursing, Pharmacy, Dentistry, and Health. Our researchers received over $230 million in grants during fiscal year 2013. Less typically, we are the only academic medical center in Utah and in a region that spans over 10% of the continental U.S., including Idaho, Wyoming, Montana, much of Nevada, and western Colorado. Two-thirds of the physicians in the state received some of their training at the University of Utah. We are one of the top three employers in the state. Our Salt Lake City facilities, satellite clinics, telehealth services, AirMed helicopters, and fixed-wing aircraft provide these regional patients access to a Level 1 trauma center, the region's only burn center, the region's only designated Comprehensive Stroke Center, and our world-renowned Huntsman Cancer and Moran Eye Centers, just to name a few. The University of Utah Health Care logs almost 1.2 million inpatient and outpatient visits annually.

Unsustainable Funding Models for Research and Education in Academic Medicine

What are some examples of the cross subsidizations from clinical to research and education? Due to the high costs of biomedical research, academic medical centers spend an additional 25-40 cents for every $1 of external research funding received. For education in Utah, our medical school covers the cost of 65% of a medical student's education, with only 5% funded by the state and 30% by tuition. Once these students graduate and enter residency, academic medical centers still cover more than a quarter of the costs of our residents' training. At the same time, we serve as the safety net for many low-income and uninsured people, providing over $100M in charity care this year.

It is clear that this model of subsidizing research and education from clinical revenues is not sustainable, and it's not right. To ensure the kind of transparency and accountability we want

in good government, we need to provide the right funding for research to the NIH directly and the right funding for education, as in GME funding, and Title VII and VIII programs, directly.

When you make these direct investments, they yield a great return. An example is the story of Angelina Jolie and the Utah Genome Project.

Utah's Large Families and the Utah Genome Project

Last year, Angelina Jolie, in an op-ed piece in the New York Times, shared her experience of taking steps to reduce her high risk of breast cancer. Jolie's mother had both breast and ovarian cancer, and her maternal grandmother had ovarian cancer, all diagnosed at younger-than-average ages. Through genetic testing, Jolie was found to have a mutation in the BRCA1 gene, and she wrote about the measures she took to prevent the cancer from afflicting her.

What's the Utah connection? In the early 1990's, after studying numerous Utah families like Jolie's, where mothers and daughters were affected by breast and ovarian cancer, researchers at the University of Utah helped to identify the BRCA1 gene. And in 1994, they sequenced the gene and created a test to determine a patient's risk for getting the disease. This discovery has saved thousands of lives and changed how providers and patients, like Jolie, treat and prevent breast cancer worldwide.

This University of Utah discovery, and our discovery of more than 30 genes, including sudden cardiac death (long QT), the APC colon cancer gene, and dozens of other diseases, have been made possible through a unique resource called the Utah Population Database, which houses massive family genealogies connected to public health and medical records—by far the largest database of its kind in the world. Thanks to the foresight of leaders like you and scientific visionaries like Francis Collins, this is just the tip of the iceberg for genomic or personalized medicine. By using the Utah Population Database, the Utah Genome Project is finding those

disease-causing genes by comparing the DNA of affected family members with those not affected by disease, in areas from autism to Alzheimer's, from cancers to heart disease. It is a remarkably powerful tool, and as Congressman Stewart knows well, Utah's large families have given us a great gift, a national treasure.

We respectfully request that your subcommittee fund the NIH at least $32 billion in FY 2015 to ensure that all of us and our children and their children, like Angelina Jolie, can outlive our family histories.

Sustaining the Health Care Workforce

As we move into an era of personalized medicine, it is also important to ensure that we have the workforce to care for us as we age and to secure a healthy future for the next generations. The AAMC estimates that by 2025, we will face an overall physician shortage of over 130,000 and a primary care physician shortage of over 65,000. At the same time, over 30 million previously uninsured Americans will gain insurance coverage, and the number of people over age 65—who use twice as much health care as younger adults—will double.

Medical schools, like ours, are doing their part to address this shortage. In the past decade, we've increased enrollment by an average of 30%. But this is only half of the solution. We must also train these new graduates before they can begin seeing patients—a difficult task, as the number of federally funded residencies has been capped since 1997. With limited GME funding, academic medical centers are increasingly reliant on other federal funding streams, including Title VII, to help support new training positions and to relieve this bottleneck.

In Utah, Title VII and Title VIII funding is especially important. Of Utah's 29 counties, 27 are designated as primary care Health Professional Shortage Areas. Moreover, Utah ranks last among the 50 states in the number of active primary care physicians per capita. Title VII and

Title VIII programs allow us to address these gaps by funding the education and training of nurses, family medicine physicians, geriatricians, and other health professionals. As the only federally funded programs dedicated for this purpose, these are crucial to ensuring that our communities—both rural and urban—receive the care they need. Therefore, we urge your subcommittee to provide $520 million for Titles VII and VIII in FY 2015.

Conclusion

In closing, we academic medical centers will continue to work with you to ensure a healthy future for America. We at the University of Utah Health Sciences are committed to leading the transformation of health care and academic medicine—to provide patients safer and better care at lower costs, to focus more on health and prevention, and to fully leverage our scientific discoveries and technologies for better patient and population health. We are designing new systems of care to address these needs, and we will train the next generations of health care providers to both succeed in and improve our health care delivery system. To do so, we need to make sure that our funding model is sustainable, transparent, and accountable. Please help us eliminate the model of cross-subsidization and ensure that funding for both research and education are sufficient to secure the health of the people of America for years to come.

Thank you once again for the opportunity to appear before you. I welcome any questions you may have.

Mr. STEWART. Thank you, Dr. Lee.

Having been up and spoken with you and toured the genome project, it is a fascinating project, and it is incredibly helpful. You mentioned clinical revenues falling $100,000,000, charity medicine, and how would that have compared with previous years?

Dr. LEE. Well, we have seen a remarkable continued increase in charity care. Last year, our charity care was about $80,000,000 and before that about in the 60s. And so, we are seeing a continued increase in charity care provided by the University of Utah Hospital.

Mr. STEWART. And that is a remarkable increase. It is 40 percent. It is——

Dr. LEE. Well, we are one of the safety net systems for the State. And increasingly, as funding for healthcare is going down, patients who are unable to afford it or physicians who are unwilling to accept low-income patients are forced to direct those patients to us.

Mr. STEWART. Okay. Thank you.

Ms. LEE. Mr. Chairman. Can I just ask you, is Utah a State that has expanded the Medicaid provisions of the Affordable Care Act?

Dr. LEE. We have not expanded Medicaid. The Governor, Governor Herbert is proposing a block grant approach, which will enable our citizens who are below the Federal poverty levels up to the level of the 133 percent to secure access to insurance through a Federal block grant.

So we will need a waiver to be granted from HHS, and he is seeking that. And we hope for your support for that as well.

Ms. LEE. I see. And do you know how that would impact the charity care that you provide? Would it level it off, go down? What would it do?

Dr. LEE. Right. It would level it off. We expect that of the $100,000,000 in charity care we provide now, it would be reduced by about $20,000,000. So we would still be providing substantial charity care, but at least it is a step in the right direction.

Mr. STEWART. Thank you, Ms. Lee.

And we commend the Governor. We think he is taking an innovative approach. We will see how that works out, but thank you.

Dr. LEE. Coming up with the Utah solution. So——

Mr. STEWART. Yes, the Utah solution. Thank you, Doctor. We appreciate it.

All right. Then we turn now to Jonathan Lewin, M.D., from the Academy of Radiological Research.

Doctor.

TUESDAY, MARCH 25, 2014.

ACADEMY OF RADIOLOGY RESEARCH

WITNESS

JONATHAN S. LEWIN, M.D., PRESIDENT, ACADEMY OF RADIOLOGY RESEARCH

Dr. LEWIN. Good morning. My name is Jonathan Lewin. I am president of the Academy of Radiology Research, a national organization representing imaging scientists, radiology societies, industry partners, and patient advocacy organizations.

Thank you for the opportunity to testify.

We respectfully recommend a fiscal year 2015 funding level of $32,000,000,000 for the NIH, and $397,000,000 for the National Institute of Biomedical Imaging and Bioengineering, the NIBIB. That is a $70,000,000 increase that will accelerate the current technological revolution in medicine, help build a cost-efficient health system based on prevention, and will stimulate one of our Nation's strongest export industries.

As a longtime NIH investigator and in my roles as a senior vice president for Johns Hopkins Medicine, and as chair of the Department of Radiology, I see firsthand the incredible work of NIH-funded scientists. However, today there are more and more anecdotes of high-scoring applications going unfunded and junior scientists who are leaving for other countries.

While both emerging and developed economies continue to prioritize public funding for medical research, the annualized rate of growth for NIH over the past decade has been 0.6 percent. This flat-line funding level will not support two essential fiscal outcomes—creating jobs by out-innovating emerging economies and lowering long-term healthcare costs through research innovation.

The academy's request of $32,000,000,000 for NIH in fiscal year 2015 represents an important step toward securing our global leadership in medical technology.

As an imaging scientist and radiologist, I have also been fortunate to be part of medicine's technological revolution. For example, today imaging is currently used in 88 percent of all diseases studied at the NIH. While it is a pleasure to see imaging being used by many scientific disciplines, it is important to recognize that they would not be possible without the technological research from the NIBIB.

NIBIB was created by Congress in 2000 to provide a home for the development and application of new and emerging medical technologies, with the goal of building a smarter, technology-enabled healthcare system. The investment in NIBIB's research is particularly valuable considering there are three tangible outputs from NIBIB research.

First, our bench-to-bedside imaging technologies that help medical professionals diagnose, treat, and monitor patients, saving millions of lives each year.

The second are new bench-to-bench research tools, such as the new imaging techniques being used in the BRAIN initiative and in the Human Connectome Project that have given other researchers game-changing new ways to advance the diseases they study.

And finally, NIBIB research provides the basic research pipeline for commercial diagnostic and therapeutic devices, one of our country's strongest export industries as identified by the Department of Commerce. NIBIB's central role in the biotechnology revolution is perhaps best demonstrated in a recent NIH patent analysis completed by the Academy of Radiology Research.

Looking at the various NIH institutes from 2003 to 2012, the NIBIB produced new pieces of intellectual property at the highest rate across NIH. Over the past decade, it required just $6,000,000 of NIBIB funding before one patent is produced, compared with $39,000,000 per patent across the NIH as a whole.

Considering the private sector invests about $3,400,000 to generate each patent on average, NIBIB is creating intellectual property at essentially a private sector level of efficiency. Perhaps even more surprising, the NIBIB's patent production over the last decade has outpaced other prominent Federal R&D programs, such as DARPA, the NSF, and NASA.

Since patents are strongly correlated with higher levels of product development, startup activity, and employment, patent output may be a key metric that policymakers would want to consider to optimize the economic and employment impact from publicly funded research.

Furthermore, since much of the downstream R&D spurred by the NIH and NIBIB patents occurs at companies located just outside of major academic centers, the committee may want to further examine the role of patent output as a key metric for growing R&D-related jobs outside of traditional academic centers. In the meantime, the administration and Congress should be proud to recognize NIH as the home to one of the leading, if not the leading, jobs-producing R&D program across the Federal Government in the NIBIB.

So we urge the committee to give strong consideration to the academy's recommended funding levels for both the NIH and NIBIB. Doing so will allow this valuable jobs-promoting research to continue improving lives and spurring new export-oriented businesses across the country.

Thank you once again for inviting the academy to testify today, and I would be happy to answer any questions.

[The information follows:]

Statement by Jonathan S. Lewin, MD, FACR
President of the Academy of Radiology Research

Public Witness Hearing on the
FY 2015 Appropriation for the National Institutes of Health
March 25, 2014

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

Good morning. My name is Jonathan Lewin, and I am President of the Academy of Radiology Research, a national organization representing imaging scientists, radiology societies, industry partners and patient advocacy organizations. Together, our organization represents the tens of thousands of academic imaging scientists and industry researchers who are developing the cutting-edge imaging technologies that continue to change the face of medicine. Thank you for the opportunity to testify before the subcommittee.

The Academy is pleased to respectfully recommend a fiscal year 2015 funding level of **$32 billion for National Institutes of Health (NIH)** and **$397 million for the National Institute of Biomedical Imaging and Bioengineering (NIBIB)**, a $70 million increase that will accelerate the current technological revolution in medicine, help build a cost-efficient health system based on prevention, and stimulate one of our nation's strongest export industries.

As a long-time NIH investigator and a senior administrator at one of the country's largest research institutions, biomedical research is near and dear to my heart. I currently have the honor of serving as the Senior Vice President of Integrated Healthcare Delivery for Johns Hopkins Medicine, as well as the Chair of the Department of Radiology and Radiological Science. Like my colleagues at other institutions, I get to see first-hand the incredible work that NIH-funded scientists are doing to save lives, improve the health care delivery model and contribute to the local economy. But while this is an exciting time for medical research – particularly within the imaging community – conversations among investigators about the future of medicine almost invariably turn to the distressing state of American science, with more and more anecdotes of high-scoring applications going unfunded, junior scientists leaving for other countries, and budding young labs being forced to close down.

If the "doubling" of NIH from 1999 to 2003 represented a "boom" in funding, the past decade unfortunately represents the "bust." Looking back to fiscal year 2004, NIH funding stood at $27.8 billion. A decade later, NIH now stands at $29.9 billion – meaning that our engine for medical

breakthroughs in the U.S. has grown a total of 5% over the past eleven years, or at an annualized rate of 0.6%. Not only have years of progress towards cures and treatments been lost, but this flat-line rate of growth is not reflective of an economy whose future depends on two essential fiscal outcomes: creating jobs by out-innovating emerging economies, and lower long-term healthcare costs made possible by research discoveries.

Looking globally, NIH Director Francis Collins stated before this Subcommittee that other nations are "ramping up their support of biomedical research because they've read our playbook." Indeed, both emerging and developed economies continue to prioritize public funding for medical research and development, relying on biomedical innovation as one of the fiscal cornerstones of their own economic recoveries. If we wish to maintain our competitive advantage in biotechnology, something that is critical to our country's economic blueprint, we must return to the days when we adequately funded the vital basic research that creates jobs, spurs economic growth and improves patient care. If the NIH budget had maintained even a modest level of 3% annual growth since 2004, NIH funding would stand at a more sustainable $38.5 billion today. Therefore, the Academy's modest request of $32 billion represents an important step towards re-securing our global leadership in medical technology, while delivering the healthcare knowledge that leads to a healthier America and the clinical innovations that can reduce our overall healthcare expenditures moving forward.

Imaging Research at NIH and NIBIB

As an imaging scientist and Radiologist, I've also been fortunate to be a part of a medicine's technological revolution, one that has brought imaging and engineering to greater prominence in the biomedical arena. Imaging is currently used in 88% of all diseases that NIH studies, while playing a leading role in a number of the NIH's signature initiatives, including the Human Connectome Project, the newly announced BRAIN Initiative, and the Alzheimer's Disease Neuroimaging Initiative. The National Cancer Institute also continues to play a critical role in cancer imaging through funding for

the American College of Radiology Imaging Network (ACRIN). Through ACRIN, the National Lung Cancer Screening Trial recently found a 20% reduction in mortality for at-risk populations using low-dose CT screening. This study is a watershed moment for those at-risk for lung cancer, and will almost immediately begin saving lives and resources by catching lung tumors earlier than ever before.

However, it is important to recognize that imaging advances such as these would not be possible without the National Institute for Biomedical Imaging and Bioengineering (NIBIB). NIBIB was created by Congress in 2000 to provide a home for the development and application of new and emerging medical technologies, with the goal of building a smarter, technology-enabled healthcare system based on early detection, prevention and personalized treatment. Since its establishment, NIBIB has supported interdisciplinary teams of physicians, bioengineers, medical physicists, chemists, computer scientists and numerous others required to advance the fields that stand at the crossroads of medicine and technology.

The investment in NIBIB's research is particularly valuable, considering there are three distinct and tangible outputs from NIBIB research: the first are ***bench-to-bedside imaging technologies*** that help medical professionals diagnose, treat, and monitor a wide array of diseases and conditions, saving millions of lives each year and avoiding unnecessary surgeries and hospital admissions. The second are ***new bench-to-bench research tools*** – such as the new imaging techniques being used in the BRAIN Initiative or the Human Connectome Project - that have given researchers in other areas of science game-changing new ways to advance the diseases that they study. And finally, NIBIB research provides the ***basic research pipeline for commercial diagnostic and therapeutic devices,*** one our country's strongest export-industries as identified by the Department of Commerce.

At Hopkins, we currently have an exciting project that embodies all three of these tangible research deliverables, and is aimed at tackling one of our country's most threatening public health concerns: obesity. This particular grant uses the image-guided injection of microbeads to embolize the

small artery in the stomach that supports a key hunger hormone called ghrelin. By finding exactly the right artery, and thus the supply of nutrients and oxygen, the interventional radiologist can inject microbeads that impede the blood supply and down-regulate the amount of ghrelin that is produced – resulting in less desire to eat and sustainable long-term weight loss. This minimally-invasive procedure has the potential to replace more expensive and risky bariatric surgery, as well as create a whole new manufacturing facility around Hopkins for the novel microbeads that make the technique possible. The application for this project recently came back with a perfect score from NIH – a number ONE priority score from peer review – but amazingly and inexplicably was rejected by the NIH Institute to which it was assigned. At that point NIBIB stepped in and, despite a budget six times smaller than the original Institute, funded the grant for all the compelling reasons that resulted in a perfect score during peer review. Thanks to the NIBIB, a cost-effective, technology-based solution is now being developed to address one of our country's most expensive and deadly public health issues.

NIBIB's central role in this technological revolution in medicine is perhaps best demonstrated in a recent NIH patent analysis completed by the Academy of Radiology Research, which is in the process of being published in the peer-reviewed scientific literature. Looking at the various NIH Institutes from 2003-2012, NIBIB produced new pieces of intellectual property, as measured by patent generation, at the highest rate across NIH. For every $100 million in NIH funding, NIBIB generated 16 patents, compared to 2.5 patents across the rest of the NIH. Put another way, it requires just $6 million of NIBIB funding before one patent is generated, compared with $39 million per patent across the NIH as a whole. Considering the private sector invests $3.4 million on average to develop one patent, NIBIB research is creating new intellectual property at private sector levels of efficiency.

To also look at the quality of patents across NIH, the Academy's analysis also looked at forward citations – which are references by future patents back to the original NIH patent. Forward citations are a well-studied metric that can help identify truly pioneering discoveries: the more forward

citations, the more downstream lines of future R&D were spurred, and the greater the odds that the original patent was the intellectual cornerstone for a budding new product or industry. In this part of the Academy's analysis, NIBIB patents averaged 13 forward citations – or 13 additional patents spurred – for every patent it created. This was nearly double the NIH average of 7.9 forward citations, and 10 times more downstream patents generated from private-sector biotechnology patents.

Perhaps even more surprising, NIBIB's patent production and quality over the last decade has outpaced other prominent federal R&D programs, such as DARPA, NSF and NASA – programs that conduct a large amount of applied science and are geared towards product development. The fact that NIBIB is perhaps the most innovative federal R&D program is a truly remarkable finding, and a testament to the speed at which the fields of biotechnology, biomedical imaging and bioengineering are moving. Since patents are strongly correlated with higher levels of product development, start-up activity, and employment, patent output may be a key metric that policymakers would want to consider to optimize the economic and employment impact from publicly funded research. In the meantime, the Administration and Congress should be proud to recognize NIH as the home to one of the leading – if not the leading – jobs-producing R&D programs across the federal government. And since much of the downstream R&D spurred by NIH and NIBIB patents occurs at companies located just outside of major academic centers, cities, and districts, the Committee may want to further examine the role of patent output as a key metric for growing R&D-related jobs outside of traditional academic centers.

Taken together with the compelling public health and global leadership factors described earlier, we urge the Committee to give strong consideration to the Academy's recommended funding levels for both the NIH and the NIBIB. Doing so will allow this valuable jobs-promoting research to continue improving lives and spurring new export-oriented businesses all across the country. Thank you once again for inviting the Academy to testify today, and I would be happy to answer any questions.

Mr. STEWART. Thank you, Dr. Lewin. Appreciate it. Appreciate your testimony.

I will introduce the next witness. And as I do that, I will excuse myself, and Dr. Andy Harris will chair the committee from this point forward.

Dr. Robert I.L. Morrison, executive director, National Association of State Alcohol and Drug Abuse Directors.

And Mr. Morrison, we welcome you and look forward to your testimony, and I will turn the chair over.

Dr. HARRIS [presiding]. You can go ahead.

TUESDAY, MARCH 25, 2014.

NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS

WITNESS

ROBERT I.L. MORRISON, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS

Mr. MORRISON. Thank you, Mr. Chairman.

I am Robert Morrison, and I serve as executive director of the National Association of State Alcohol and Drug Abuse Directors.

Thank you for the opportunity to testify as it seems we are in the midst of a national conversation about addiction, conversation that was in part generated by the tragic and high-profile deaths of famous actors and entertainers.

More and more, the dialogue is moving from the talk shows to State capitals, from entertainment magazines to town hall meetings, and with good reason. Overall, more than 23 million people, age 12 or older, needed treatment for an illicit drug or alcohol problem in 2012. Yet only 2.5 million people actually received the treatment they needed.

According to SAMHSA, the number of Americans who are abusing or dependent on pain relievers just about doubled from the years 2004 to 2012. The number of persons with heroin dependence or abuse did double from 2002 to 2012, but perhaps most chilling and heartbreaking, there were over 16,000 drug poisoning deaths involving prescription painkillers in 2010.

The key questions are what are we doing now? What more can be done? And why is this so important?

NASADAD released a report in 2010 to describe actions our members are taking. Virtually all States label prescription drug abuse as an important priority, with 11 States noting it was the most important.

Thirty-five States have some type of task force or interagency body designed to address the topic. Eighty-three percent of our members are engaged in efforts to educate the public, with more than half targeting efforts specifically at young adults and adolescents.

In States across the country, we have seen campaigns to help reduce overdose deaths. In California, in 2008, for example, a task force membership led by the State substance abuse agency included over 40 practitioners, law enforcement, researchers, and others.

As we turn to Congress for help, our number-one priority is the Substance Abuse Prevention and Treatment Block Grant, a program distributed by formula that supports services for over 2 million Americans each year. Working with SAMHSA, States track outcomes and ensure efficient, effective, and accountable use of resources.

We know, for example, at discharge from treatment 73 percent people receiving block grant services were abstinent from illegal drugs, and 81.7 percent were abstinent from alcohol use. By statute, 20 percent of the block grant funds are dedicated to much-needed substance abuse prevention services.

As we look at other recommendations for SAMHSA, we highlight the following. We recommend $190,500,000 in fiscal year 2015, for an increase of $15,000,000 for the Center for Substance Abuse Prevention. States believe that CSAP-funded, State-led initiatives on underage drinking using a systematic planning approach played a key role in the more than 30 percent drop in underage binge drinking over the past 10 years. We strongly support the Partnerships for Success grants, which built on this framework now and focus in part on prescription drug abuse.

For the Center for Substance Abuse Treatment, NASADAD strongly recommends restoring the administration's proposed cut of $64,000,000. We recommend a new discretionary grant to expand treatment for opioid dependence, including increased access to medication-assisted treatment. We also support proposed funds for CSAT to promote more coordination between primary care and addiction services.

My board chairman, Mark Stringer from Missouri, he asked me to thank you. Thank you for helping Nora, who overcame 23 years of addiction, including the loss of her children, her job, her home. And with block grant-supported services, she is now a responsible mother, certified peer specialist, and taxpaying citizen.

He asked me to thank you for helping Gilbert, who came to block grant-funded programs with only the clothes on his back and a bag of dirty laundry. After losing everything, Gilbert is now in recovery for over 8 years and works as a case worker.

Finally, he asked me to thank you for helping Brittany, who overcame 14 years of addiction with services, and she is now a responsible mother and a college student.

Please accept my gratitude on behalf of millions of other parents across the country for the prevention services you provide so that kids like my own have a bright and limitless future. We stand ready to work with the committee. We understand you have many challenging decisions to make on these important issues, but we appreciate your support.

Thank you.

[The information follows:]

House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies

Public Witness Hearing – March 25, 2014

Testimony of Robert I.L. Morrison, Executive Director,

National Association of State Alcohol and Drug Abuse Directors (NASADAD)

In millions of dollars

Program	FY 2014 Appropriation	President's Proposed FY 2015 Budget	FY 2015 NASADAD Recommendation
SAMHSA Substance Abuse Prevention and Treatment (SAPT) Block Grant	$1,819.8	$1,819.8	$1,879.8
SAMHSA Center for Substance Abuse Treatment (CSAT)	$361.4	$297.4	$361.4
SAMHSA Center for Substance Abuse Prevention (CSAP)	$175.5	$185.5	$190.5
NIH National Institute on Alcohol Abuse and Alcoholism (NIAAA)	$445	$446	$476.2
NIH National Institute on Drug Abuse (NIDA)	$1,015.8	$1,023.3	$1,086.9

Chairman Kingston, Ranking Member DeLauro, Members of the Subcommittee, I am Robert Morrison and I serve as Executive Director of the National Association of State Alcohol and Drug Abuse Directors or NASADAD.

The tragic deaths of famous entertainers have launched a national conversation about addiction, with a particular emphasis on prescription drugs and heroin. Pain killers were involved in 17,400 overdose deaths in 2010 (CDC); the number of persons with heroin dependence/abuse doubled from 2002 to 2013 (NSDUH); and nearly half of the young people who injected heroin surveyed in three recent studies abused prescription drugs before using heroin. Some noted that heroin was cheaper and easier to acquire (NIDA). In the end, over 23.1 million people aged 12 or older needed treatment for an illicit drug or alcohol problem in 2012. Unfortunately, only 2.5 million received treatment in a specialty facility. As a result, 20.6 million people needed but did not receive these lifesaving services. This complex problem requires a comprehensive approach – and this comprehensive approach must include a strong investment in substance abuse prevention, treatment and recovery.

As we consider action, it is important to examine how we allocate our health dollars. SAMHSA's *National Expenditures for Mental Health Services and Substance Abuse Treatment, 1986-2009* (2013) found that substance abuse spending represented only 1.0 percent of total healthcare expenditures in 2009 ($24 billion for substance abuse and $2.3 trillion for all health).

We know this small investment cannot keep up with the large costs of not treating addiction or preventing the problem in the first place. Illegal drugs, alcohol and tobacco together costs society $610 billion per year: $193 billion for illegal drugs; $224 billion for alcohol; and $193 billion for tobacco (ONDCP 2011; Bouchery et al., 2011; CDC). These costs were linked not only to medical consequences of alcohol/drug use, but also crime, lost earnings, motor vehicle crashes, and more.

A 2004 study in the Journal of the American Medical Association (JAMA) concluded that illicit drugs, alcohol and tobacco were each among the top nine leading "actual causes of death" defined by the Centers for Disease Control and Prevention (CDC). Tobacco, alcohol and illicit drugs led to the deaths of 530,000 Americans in 2000.

The good news is that addiction services save lives and taxpayer dollars. NIDA estimates that for every dollar spent on addiction treatment programs, there is an estimated $4 to $7 reduction in the cost of drug related crimes. When savings related to health care are included, the total savings can exceed costs by a ratio of 12:1 (NIDA InfoFacts, 2007). A study for SAMHSA concluded that evidence-based school prevention savings exceeded costs by a ratio of approximately 18 to 1 (Miller and Hendrie, 2008).

State substance abuse agencies lead innovations to address the many emerging issues impacting citizens across the lifespan, including heroin and prescription drug abuse. Our members also note the benefit of a strong partnership with SAMHSA, and recommend actions by

Congress to ensure a strong and vibrant agency – which includes a strong Center for Substance Abuse Treatment (CSAT) and strong Center for Substance Abuse Prevention (CSAP).

Top Funding Priority for FY 2015 –Substance Abuse Prevention and Treatment (SAPT) Block Grant: NASADAD recommends $1,880,000,000 for the SAPT Block Grant in FY 2015 – an increase of $60 million over FY 2014. The SAPT Block Grant is an effective and efficient program distributed by formula to all States, District of Columbia and Territories. The SAPT Block Grant has been successful in expanding treatment capacity and supported over 2.5 million persons to get treatment and/or recovery services through State systems in FY 2011. Outcome data collected by State substance abuse agencies demonstrated positive results from SAPT Block Grant-funded programs: at discharge, 73.5 percent of people receiving treatment were abstinent from illegal drugs; 81.7 percent people were abstinent from alcohol use. States also reported an increase in clients with no criminal justice involvement.

The SAPT Block Grant represents a core component of each State's substance abuse prevention system. By statute, at least twenty percent of the SAPT Block Grant must be spent on primary substance abuse prevention services. The SAPT Block Grant "prevention set-aside" represents, on average, approximately 65 percent of State substance abuse agencies' budgets for substance abuse prevention services. In fact, the set-aside represents 100 percent of the agency's prevention budget in 6 States and over 75 percent of the agency's prevention budget in 16 States.

Center for Substance Abuse Prevention (CSAP): NASADAD recommends $190.5 million in FY 2015 or an increase of $15 million compared to the FY 2014. NASADAD strongly supports CSAP's *Strategic Prevention Framework (SPF) Grants*. The SPF program uses a public health planning model that utilizes evidence-based services to address areas of greatest need. The *Partnerships for Success Program* builds on the achievements of the SPF.

States believe that their SPF initiatives, which primarily focused on underage drinking, played a key role in the more than 30 percent drop in underage binge drinking over the past ten years (NSDUH). Since FY 2012, these grants have focused on prescription drug abuse/misuse and underage drinking.

NASADAD strongly supports SAMHSA's new proposal titled *Strategic Prevention Framework Prescription Drug Abuse and Overdose Prevention (SPF Rx)*. This $10 million investment would allocate funds to States to bolster and complement current efforts through the use of evidence-based practices, use of data for prevention planning, and environmental strategies. SAMHSA proposes to support planning grants for up to 20 other States to build capacity to address prescription drug abuse and overdose prevention efforts.

The Association also supports much needed funding for the *Sober Truth on Preventing Underage Drinking [STOP] Act*. NASADAD recognizes the leadership of Congresswomen Roybal-Allard, a member of this Subcommittee, for her work on underage drinking.

Center for Substance Abuse Treatment (CSAT): NASADAD recommends $361,460,000 in FY 2015 or restoring the Administration's proposed cut of $64 million.

NASADAD supports SAMHSA's proposed $20 million for a new initiative – the *Primary Care and Addiction Services Integration (PCASI) Program*. This program would establish projects to provide coordination and co-location of primary and specialty care services in community-based substance abuse treatment settings. The goal of the program would be to improve the health of those with substance use disorders and reduce costs. NASADAD urges action to ensure the initiative includes a direct role for State substance abuse agencies.

NASADAD applauds SAMHSA for elevating workforce issues as a top priority. We urge action to ensure that resources for workforce issues, including any proposed FY 20015 funding,

are allocated in an equitable manner among programs focused on mental health workforce initiatives and addiction workforce initiatives – including substance abuse prevention.

NASADAD recommends a new discretionary grant to State substance abuse agencies to better meet the treatment needs of people with opioid dependence, including dependence on prescription drugs or heroin. This grant would help State substance abuse agencies work with hospitals, emergency rooms, health clinics and others to develop innovative strategies to reduce the impact of opioid misuse and abuse in their State. This new discretionary grant should specifically reference the ability of States to use these funds for medication assisted treatment (MAT) and to develop the capacity to deliver MAT more broadly and effectively. NASADAD defines MAT as use of FDA-approved medications for the treatment of opioid and alcohol dependence and addictions.

NASADAD is concerned about the proposed $64 million cut to CSAT. This reduction would eliminate the Access to Recovery (ATR) program, a grant to States that supports both clinical and recovery support services (a cut of $50 million); cut the criminal justice portfolio by $10.5 million ($75 million to $64.5 million); reduce the minority AIDS initiative by $6.9 million ($65.7 million to $58.8 million) and cut the Addiction Technology Transfer Centers [ATTCs] by $1 million ($9 million to $8 million). We seek full restoration of CSAT's budget.

National Institute on Drug Abuse (NIDA) and National Institute on Alcohol Abuse and Alcoholism (NIAAA): NASADAD supports $1,086,900,000 for NIDA and $476,200,000 for NIAAA. Both Institutes engage in critical research that ultimately impacts the people served by State substance abuse agencies.

Thank you for the opportunity to testify and thank you for your support of substance abuse prevention, treatment and recovery services.

Dr. HARRIS. Thank you very much, Mr. Morrison.

Next, we will have David Pickler from the National School Board Association.

Mr. Pickler, have a seat. Thank you very much for being here.

TUESDAY, MARCH 25, 2014.

THE NATIONAL SCHOOL BOARD ASSOCIATION

WITNESS

DAVID A. PICKLER, PRESIDENT, THE NATIONAL SCHOOL BOARD ASSOCIATION

Mr. PICKLER. Thank you, Mr. Chairman, Ranking Member DeLauro, and members of the subcommittee.

I appreciate the opportunity to share the National School Board Association's perspective on Federal investments in our Nation's students and public school districts. As president of the National School Board Association, I will speak with the collective voice of more than 90,000 local school board members who govern more than 13,000 local school districts and who educate America's 50 million school children.

Working with and through our State associations, NSBA advocates for equity and excellence in public education. Recently, we launched a campaign called Stand Up 4 Public Schools to further expand support for and commitment to public education.

The intent of this public advocacy initiative is to empower—to help every child achieve world-class standards and a brighter future. Public education is the most important function of local government, and local school districts collectively are America's largest employers, with over 6.2 million employees.

Locally, I have served as a member of the Shelby County Board of Education for the past 16 years. I am also the owner of four successful small businesses, and I understand how important education is to our economy. There is no more important function for a community than to empower its children with a quality education, regardless of their zip code, race, or religion.

I would like to discuss several issues of significance to America's public schools. First, the Individuals with Disabilities Education Act, IDEA, has helped address the special needs of millions of children. IDEA was envisioned as a Federal-State partnership in which Congress would provide 40 percent of the funding and the States 60 percent.

However, the Federal share of this commitment has not yet been achieved. The impact of underfunding IDEA has caused reductions to other programs, particularly education reforms, at a time when more innovation is needed. NSBA applauds the bipartisan support in Congress to achieve a path toward full funding for special education, and thanks the cosponsors of the IDEA Full Funding Act, H.R. 4136.

We urge your strong support for this legislation and also urge you to designate IDEA as a top priority in the fiscal year 2015 appropriations, as well support for local school board flexibility in achieving true reform.

Secondly, the increase in competitive grants programs has prompted significant concern. New programs are being created while foundational programs with proven success such as such as IDEA and Title I grants for disadvantaged students are at stagnant funding levels. Increasing the Federal share of funding of these key programs is paramount.

In briefings with school boards receiving competitive grants, many of our districts are forced to devote more time towards reporting and compliance efforts than in pursuing gains in academic achievement.

Equally important, the very districts that have the greatest need for these competitive grant funds do not have the resources or the capacity to apply for or leverage such funding. So when these grants are awarded, we are creating an even greater divide between affluent districts and those in underserved communities with fewer resources.

Third, NSBA applauds the administration's budget proposals to expand access to early education as well as technology resources in our classrooms. These priorities will help prepare students with 21st century skills and the knowledge needed to thrive.

However, the administration's proposed funding levels for Title I, IDEA State grants, Impact Aid, and career and technical education do not meet the needs of our students and districts.

Fourth, many of our districts employ a range of options to address the loss of funding due to sequestration, from staff reductions to curtailing extracurricular activities. Districts reduced professional development for teachers, increased class sizes, cut salaries, deferred maintenance, delayed purchases, and reduced course offerings and transportation services.

Furthermore, districts that receive Impact Aid funding were most negatively impacted and experienced immediate budget cuts. Impact Aid helps school districts to educate children whose parents are in our armed forces, as well as children who reside on Native American trust lands.

For many of our Impact Aid districts, Federal funding comprises as much as 30 percent or more of their budgets. And unlike other districts, they do not have the property tax revenues to rely on, given these nontaxable Federal lands and installations on their boundaries.

Our school districts have weathered the storm. But the storm cannot and must not continue. Looking to fiscal year 2016, we urge you to proactively develop a plan that will protect education investments as a critical asset for economic stability and American competitiveness.

In conclusion, I would like to share research from NSBA's Center for Public Education regarding education's return on investment. For each student who graduates from a high school, the U.S. economy receives an additional $260,000 in earnings, taxes, and productivity over his or her lifetime compared to a student who doesn't graduate.

Also, studies indicate that for every dollar invested in our youngest students, society would reap at least $3 in additional tax revenue, as well as significant savings in lower public assistance cost. And students who get a strong start are more likely to graduate

and eventually move on to college. Clearly, your work here is essentially to the success of our students and nation.

Again, thank you for this opportunity, and we appreciate your leadership and look forward to working closely with you. Mr. Chairman, I would request that my full statement be included in the record.

[The information follows:]

Testimony of David A. Pickler, President

National School Boards Association

before the

Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, Committee on Appropriations

United States House of Representatives

March 25, 2014

Chairman Kingston, Ranking Member DeLauro, and Members of the Subcommittee, I appreciate the opportunity to share the National School Boards Association's (NSBA) perspective on federal investments in our nation's students and public school districts.

As President of the National School Boards Association, I speak with the collective voice of more than 90,000 local school board members who govern more than 13,000 school districts educating America's 50 million public school students. Working with and through our state school boards associations, NSBA advocates for equity and excellence in public education. Recently, we launched a campaign called "Stand Up 4 Public Schools," to further expand support for, and commitment to, public education. The intent of this public advocacy initiative is to create opportunities for the tens of millions of public education stakeholders and advocates to seize the bully pulpit, promoting efforts to help every child achieve world-class standards and a brighter future. Public education is the most important function of local government; and, local school districts are collectively America's largest employer with nearly 6.2 million employees.

Locally, I have served as a member of the Shelby County Board of Education in Memphis, Tennessee for the past 16 years, where we are committed to ensuring that every child is reading at grade level and is given the opportunity to succeed, regardless of their circumstances.

I am also the owner of four successful small businesses; and, I understand how important education is to our economy. There is no more important function for a community than to empower its children with a quality education, regardless of their zip code, race or religion.

Specifically, I would like to discuss federal investments in special education; the growth of competitive grant programs; the Administration's recent budget request; and, the effects of sequestration on our schools.

First, the *Individuals With Disabilities Education Act (IDEA)* has helped address the special needs of millions of students. IDEA was envisioned as a federal-state partnership in which Congress would provide 40 percent of the funding and the states 60 percent. However, the federal share of this commitment has not been achieved yet. In our school districts, the impact of underfunding IDEA has caused reductions to other programs, particularly education reforms, at a time when more innovation is needed. NSBA applauds the bipartisan support in Congress to achieve a path toward full funding for special education and thanks the co-sponsors of the IDEA Full Funding Act (H.R. 4136). We urge your strong support for this legislation and also urge you to designate IDEA as a top priority in the Fiscal Year 2015 appropriations bill.

Secondly, the increase in competitive grants programs has prompted significant concern, in that new programs are being created while foundational programs with proven success--such as IDEA and Title

I grants for disadvantaged students--are at stagnant funding levels. Increasing the federal share of funding for these key programs is paramount. In briefings with school boards whose districts received competitive grant awards, I learned that a number of these districts is forced to devote more time towards reporting and compliance efforts, rather than the gains sought in academic achievement. Equally important, the very districts that have the greatest need for these competitive grant funds do not have the resources and capacity to apply for and leverage such funding. So when these grants are awarded, we could be creating an even greater divide between districts that have the wherewithal and those in underserved communities with fewer resources. Again, NSBA urges you to maximize investments in IDEA and Title I first.

Third, NSBA applauds the Administration's budget proposals to expand access to early education as well as technology resources in our classrooms. These priorities will help prepare students with the 21st Century skills and knowledge needed to thrive. However, the Administration's proposed funding levels for Title I, IDEA State Grants, Impact Aid, and Career & Technical Education do not meet the needs of our students and districts.

Fourth, many of our districts employed a range of options to address the loss of funding from sequestration, from staff reductions to curtailing extracurricular activities. Districts reduced professional development for teachers, increased class sizes, cut salaries, deferred maintenance, delayed purchases, reduced course offerings, and altered bus routes and transportation services. Furthermore, our districts that receive Impact Aid funding were affected significantly, and experienced immediate budget cuts. Impact Aid helps school districts that educate children whose parents are in the armed forces, as well as children who reside on Native American trust lands. For many of our Impact Aid districts, federal funding comprises as much as 30 percent or more of their budgets; and,

unlike other districts, they do not have property tax revenues to rely on, given the nontaxable federal lands and installations within their boundaries. Our school districts have weathered the storm; but, the storm cannot and must not continue. Looking to Fiscal Year 2016, we urge you to proactively develop a plan that will protect education investments as a critical asset for economic stability and American competitiveness.

In conclusion, I would like to share these points-of-information from NSBA's Center for Public Education regarding the return on investments in education. For each student who graduates from high school, the U.S. economy realizes an additional $260,000 in earnings, taxes, and productivity over his or her working lifetime, compared to a student who does not graduate. Also, several studies indicate that for every dollar invested in our youngest students, society reaps at least $3 in additional tax revenue, as well as significant savings from lower public assistance spending, as students who get a strong start are far more likely to graduate from high school and eventually college. Therefore, your work here is essential to the success of our students and nation.

Again, thank you for this opportunity. NSBA appreciates your leadership and looks forward to working closely with you during the appropriations process. I welcome your questions at the appropriate time.

Mr. KINGSTON [presiding]. Without objection.

Ms. DeLauro, any questions?

Ms. DELAURO. I don't have questions. I would just say, first of all, many thanks for your testimony. I think it is important to note that 40 percent commitment that the Federal Government made is now at 16 percent.

Also with regard to both IDEA and Title I, quite frankly, we were unable to get the appropriations for those two programs to presequester levels. We got to about 81 or 85 percent with them, which is not sufficient, particularly when Title I is really the lifeblood of our public education system.

I am happy to say that we did do some increasing of Impact Aid, but I think your points are well taken, and I appreciate your testimony.

Thank you.

Mr. KINGSTON. Ms. Lee.

Thank you very much, and we will have your full statement.

Mr. PICKLER. Thank you very much. Appreciate it.

Mr. KINGSTON. Thanks.

Now policy director for Harm Reduction Coalition, Mr. Daniel Raymond.

Thank you very much.

TUESDAY, MARCH 25, 2014.

HARM REDUCTION COALITION.

WITNESS

DANIEL RAYMOND, POLICY DIRECTOR, HARM REDUCTION COALITION

Mr. RAYMOND. Thank you.

And I would like to thank the chair and ranking member and members of the subcommittee for the opportunity to talk about opioid overdose prevention.

As my colleague Mr. Morrison discussed, we have seen a great deal of media attention focused on this issue, particularly in recent months. But this has been a growing issue for well over the last decade.

We have seen from CDC the latest figures indicate that in 2010 alone, deaths from opioid overdoses—and by opioids, I am referring to both prescription opioids such as painkillers as well as heroin—totaled 20,000. And we have a lot of strategies in place that we are working on to try to get a handle on the root causes of this issue.

We support these efforts, but we feel that we need to think more about taking two different tracks. That the root causes of this opioid epidemic that we have seen over the last 15 years, that we have efforts looking at prescribing patterns, looking at regulatory authorities, looking at patient and provider education.

But we also have an opportunity from emerging strategies to deal with the immediate risk of overdose death. We promote strategies, including the broader access of a medication called naloxone. In my written testimony, I quote Dr. Nora Volkow of National Institute on Drug Abuse talking about the role that this drug plays

as an opioid antagonist that blocks the immediate effects for somebody experiencing overdose and can revive them.

It is a generic drug that is safe to use that is more and more broadly being used by lay persons, including first responders, police officers, family members, and peers and people in the position to respond to an opioid overdose. We have had 18 States enact legislation to broaden the availability of naloxone based on the rationale that the person best prepared to respond to an overdose is the person right there on the scene.

As we ask people and educate them to recognize the signs of an overdose to call 911, if possible to administer rescue breathing, we also feel that just like an epi pen, we can arm them with the tools of having a medication on hand in the household that can immediately counteract the effects of an overdose until help arrives. And that is why 18 States have enacted this legislation and are expanding access to naloxone in various ways. Just last week, Georgia's legislature passed a bill to expand access to naloxone as well that is awaiting the Governor's signature.

We think that there is much more room to scale up the Federal response, even as we have seen a groundswell of efforts at the State and community level to respond to opioid overdose prevention. In the President's budget, $26,000,000 is requested, $16,000,000 to CDC and $10,000,000 to SAMHSA, to strengthen some of their efforts around those underlying causes of prescription drug overdose. We think that those are valuable initiatives, and we are supportive of them.

We also feel that there is an immediate need until the fruits of those efforts come to bear that there will be another 10,000, 20,000 people dying if we don't take immediate efforts to expand access to naloxone. For that reason, we are requesting and recommending that through the Centers for Substance Abuse Treatment at SAMHSA, which is well positioned to work with drug treatment programs around the country and recovery services, to provide access to naloxone. Five million dollars could go a long way in reducing overdose mortality.

We also think that there is a strong public health role here, and we believe that CDC entry could complement the money that they are proposing for the core violence and injury prevention programs to focus on prescription drug overdose to ensure that there is a component to expand access to naloxone and educate communities and family members about the causes and signs and symptoms of overdose.

And in closing, I just want to say that when I asked last night for some of my colleagues to talk about the names of people who have been revived by naloxone in the community, I was flooded by names in my inbox. From Connecticut, Mark and Joey. From Georgia, Taylor and Steve. From California, Whitney. So many others from New York, Oregon, Michigan, across the country.

This is a really powerful tool, and this is a really urgent time to take action. So I thank the subcommittee for its attention and focus to the issue of opioid overdose prevention and welcome any questions.

[The information follows:]

Testimony on Opioid Overdose Prevention

Daniel Raymond, Policy Director, Harm Reduction Coalition

Presented on March 25, 2014 to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

I would like to thank Chairman Kingston, Ranking Member DeLauro, and the Members of the Subcommittee for the opportunity to speak today. I am here to provide testimony on reducing opioid overdose mortality, and to request $5 million in funding for CDC and $5 million in funding for SAMHSA to expand critical, life-saving interventions.

The opioid overdose epidemic has reached crisis proportions in recent years. The Centers for Disease Control and Prevention reports that in 2010, opioids – including both prescription painkillers and heroin – were responsible for nearly 20,000 overdose deaths. While prescription painkillers continue to account for the majority of opioid overdoses, deaths from heroin overdose increased by 45% between 2006 and 2010, fueling concerns in several parts of the country that progress in reducing prescription painkiller misuse is being offset by a dramatic rise in heroin use and its attendant social and health consequences, including addiction, hepatitis C, and overdose. For example, in Kentucky, a state on the forefront of comprehensive approaches to the prescription drug overdose epidemic, the Kentucky Injury Prevention and Research Center recently reported that while overall drug overdose deaths have leveled off from 2011 to 2012 after a decade of dramatic increases, promising declines in the number of

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prescription painkiller deaths have been accompanied by a 207% increase in heroin-related overdose deaths from 2011 to 2012.

For these reasons, Harm Reduction Coalition believes that as efforts continue to mount a comprehensive response to prescription painkiller overdoses, it is necessary to incorporate the intertwined rise in heroin misuse and adopt a broader strategic framework to address all opioids. An opioid epidemic framework would maintain and intensify the array of activities such as those aimed at opioid prescribing practices and monitoring programs, safe disposal, patient and public education, regulatory and enforcement actions, and expansion of effective addiction treatment and recovery services. At the same time, the broader opioid epidemic framework recognizes the vital need for additional public health interventions and opportunities, including the role of expanded access to naloxone, alongside heightened attention to the risks of hepatitis C and other blood-borne viruses transmissible through injection drug use.

Naloxone is a generic medication which acts as an opioid antagonist, blocking the effects of opioids such as painkillers or heroin and capable of reviving individuals from opioid overdoses. A substantial body of research and practice has demonstrated that naloxone is safe and effective in the hands of laypersons; in the words of Dr. Nora Volkow, Director of the National Institute on Drug Abuse, "several experimental overdose education and naloxone distribution (OEND) programs have issued naloxone directly to opioid users and their friends or loved ones, or other potential bystanders, along with brief training in how to use these emergency kits. Such programs have been shown to be an effective, as well as cost-effective, way of saving lives."

Dr. Volkow cites data published by CDC showing that through 2010, overdose education and naloxone distribution programs reported preventing over 10,000 opioid overdose deaths across the country. As of this month, eighteen states have passed legislation to facilitate broader access and utilization of naloxone, ranging from Kentucky to Connecticut, Ohio to California; Georgia passed naloxone legislation on March 18th which now awaits the governor's signature. These overdose education and naloxone distribution programs vary in setting and scope. In North Carolina, Project Lazarus trains physicians to co-prescribe naloxone to pain patients receiving opioids. In Massachusetts, support groups for parents with children struggling with opioid dependence are trained and provided with naloxone. In Rhode Island, naloxone is provided through pharmacies. In Kentucky, some of the strongest advocates for naloxone have been the addiction recovery community. In New York, my organization has provided naloxone training to dozens of drug treatment programs, syringe exchange programs, shelters, and law enforcement agencies. In other parts of the country, overdose education and naloxone distribution programs are launching in emergency departments, jails, and Veterans Administration Medical Centers.

These programs are gaining increased federal attention; in the last month, the Attorney General echoed the Office of National Drug Control Policy in calling upon first responders and law enforcement officers to be trained and equipped with naloxone. The Agency for Healthcare Research and Quality highlighted the Massachusetts overdose education and naloxone distribution program and featured accompanying quality tools, including an overdose and naloxone program manual from the Harm Reduction Coalition. Last year, the Substance Abuse and Mental Health Services Administration (SAMHSA) released an opioid overdose toolkit

featuring naloxone. NIDA and FDA have worked to support and facilitate the development of new, consumer-friendly formulations of naloxone. The Ohio Department of Health's Violence and Injury Prevention Program has used a portion of its CDC injury prevention funding to expand Project DAWN, an overdose education and naloxone distribution program, to additional counties.

The President's FY 2015 budget requests $26 million to prevent prescription drug overdose, of which $16 million would expand CDC's Core Violence and Injury Prevention Program grants to states, with an expected $10 million directed to prescription drug overdose activities, and $10 million to SAMHSA would fund state planning grants to develop prevention strategies for prescription drug abuse. The Harm Reduction Coalition supports these proposals, and believes that these resources would be valuable in establishing a foundation to reverse the prescription drug overdose epidemic. We also believe that additional emergency funding is necessary to stem the tide of opioid overdose from both prescription opioids and, increasingly, heroin. Within the context of a comprehensive approach to the opioid epidemic, including expanding access to addiction treatment and recovery, the Harm Reduction Coalition views the rapid expansion and scale up of overdose education and naloxone distribution programs as an urgent and underfunded priority to save lives.

To that end, we request that $5 million be provided to CDC Injury Prevention and Control to support opioid overdose fatality prevention efforts within state and local health departments and community-based organizations to strengthen their ability to deliver overdose recognition and intervention training and education, and expand access to rescue medications and other evidence-based strategies.

We also request that $5 million be provided to SAMHSA's Center for Substance Abuse Treatment to support community-based opioid overdose fatality prevention efforts, with a focus on those initiatives that provide overdose recognition and intervention training and education, access to rescue medications, and facilitate linkage to treatment and recovery services.

Across the country, emerging overdose education and naloxone distribution programs rely on limited funding to meet a growing need. The availability of targeted federal funds through both the public health and addiction treatment and recovery communities would hasten the expansion of these programs to meet growing need and demand.

In the battle against opioid overdose, there is much to be done, and no time to lose. We need a twofold approach of long-range efforts to address the underlying causes and factors which led to the initial rise in prescription opioid misuse, coupled with immediate actions to avert additional deaths and tragedies in the short-term. As a person who has lost friends and loved ones to opioid overdose, and listened to the stories of grieving parents who only wish someone had told them about naloxone before it was too late for their children, I respectfully ask for your consideration of our requests.

If you have any questions, or would like more information or data on naloxone, please feel free to contact me: Daniel Raymond, raymond@harmreduction.org, (212) 213-6376 x29. Thank you for your attention and consideration.

Mr. KINGSTON. Thank you, Mr. Raymond.

Actually, I do have a couple questions. Number one, I want to make sure that you know that there is a lot of bipartisan support on this. The number-one advocate, particularly as respects to this committee, is our chairman, Hal Rogers, which is why Kentucky is so far ahead of the curve.

But I know several years ago, he pulled a group of us together on a bipartisan basis to become more aware of what the prescription drug abuse problem is in our country, and we became aware of pill mills and the migration of them from Florida to other parts of the country, as Florida cracked down on them.

But I wanted to ask you, in terms of your testimony with this increase of heroin abuse so, therefore, we can conclude that heroin is coming back as a drug of choice? Do you want to expand on that any?

Mr. RAYMOND. Sure. I think that what we have seen is that where we have had a lot of misuse of prescription opioids, such as Oxycontin and Vicodin, that a proportion of those people become dependent on the opioid and find themselves switching to heroin because it is easily available. It is more affordable. It can be cheaper.

So the heroin market has moved in to a lot of areas that had not experienced a lot of heroin use before and is becoming a substitute drug for people who had become dependent on prescription opioids.

Mr. KINGSTON. And in terms of drug abuse in America, how much of it is prescription drug versus illegal drugs? Do you have a number on that?

Mr. RAYMOND. Well, putting aside marijuana, which is the most broadly misused illicit substance, that prescription painkiller misuse outweighs heroin use currently. I think the risk is that we don't want to see people who develop or experimented with prescription painkillers transitioning to heroin use because it can be far more dangerous, both in terms of overdose risk and also in terms of risk, if people are injecting, of acquiring HIV, hepatitis C, or other diseases.

So while we commend the focus on prescription drug misuse, we also think we can't afford to ignore the rising numbers of heroin and that these are two sides of the same coin.

Mr. KINGSTON. And before I yield to my ranking members, I wanted to ask I wasn't familiar with naloxone and being used as an epi pen somewhat. But that is, to me, something that is very interesting that we should be supporting.

So I will yield.

Ms. LEE. Yes, thank you very much.

Thank you very much for your very scary testimony, in fact. And we have got to really talk about this and how we address it. And also needle exchange. I just want to ask you. In your written testimony, you mentioned injection drug use.

In 2010, we worked with then-Chairman Obey to find a way, a workable compromise on Federal funding for needle exchange programs. Much, of course, to my dismay, the funding ban is back in place now at a time when we are making good progress in fighting, for example, HIV and AIDS and hepatitis.

And so, I know that the data are limited, but do you have a handle on what extent the Federal ban on funding for needle exchange programs, how that has impacted our ability to really reach injecting drug users, who are especially vulnerable to these, well, secondary diseases?

In many ways, some of the data has shown that once, you know, a drug user is in for the needle exchange, you have the opportunity then to provide the counseling and the support to help that individual stop using drugs. What has your experience been, and what do you think about this Federal ban on IV drug users in terms of the Federal ban on needle exchange?

Mr. RAYMOND. Sure. Thank you, Congresswoman.

And I also wanted to acknowledge the support of your office for our California office, which is based in your district.

I think that there is a lot of challenges, and there is a lot of thinking that is this—is syringe exchange something that the Federal Government should be spending money on? Is it something that the taxpayers should be spending money on? And there has been a lot of controversy over this over the last 20 years. So it is not surprising that this controversy remains in Congress, too.

I will say that my organization just spent some time in northern Kentucky training about 100 people on some of these issues that we have been talking about. There were a lot of people who came because they were struggling with the overdose issue.

We had some parents groups, a lot of people from drug treatment programs, and a lot of people from the surrounding community of both northern Kentucky and southern Ohio, where there has been a huge problem with addiction, with overdose, and increasingly with hepatitis C. And we had a bunch of workshops.

The most popular one we did was on syringe exchange, where we had people in northern Kentucky saying we don't know what to do. We are suddenly seeing a lot of hepatitis C cases because people are injecting, and we don't have anything in place. We have never had to deal with this before. We have never seen this before. We don't have a syringe exchange. We don't have enough beds for drug treatment.

Just across the river in Cincinnati, they had just opened up their first needle exchange, and they were eager to hear how they could find support. They have been able to cobble together some private money, some donations to get started. But what we heard is that in these places that have never had to deal with injection drug use at this scale before, they are trying to figure out solutions.

And one of the solutions that many of them are looking at is syringe exchange. And when they look there, they don't find resources to support it, and I think that is because of the constrained budget environment. And the Federal prohibition on funding is going to be an obstacle for places that choose to adopt that intervention because it is right for their communities.

This will have a ripple effect on new hepatitis C cases, and our biggest concern is as we have seen hepatitis C infections, new infections double within 2 years, according to CDC data, in the wake of this epidemic, can HIV be far behind?

Ms. LEE. Thank you.

And Mr. Chairman, I hope that we can revisit this at some point. Thank you.

Mr. KINGSTON. And our next witness is Ms. Rebecca Salay, Director of Governmental Relations for the Trust for America's Health.

Welcome to the committee.

TUESDAY, MARCH 25, 2014.

TRUST FOR AMERICA'S HEALTH

WITNESS

REBECCA SALAY, DIRECTOR OF GOVERNMENT RELATIONS, TRUST FOR AMERICA'S HEALTH

Ms. SALAY. Thank you very much, Chairman Kingston and Ranking Member DeLauro.

I am with the Trust for America's Health, a nonprofit, nonpartisan organization dedicated to saving lives by working to make disease prevention a national priority.

I want to start by thanking you for recognizing the importance of public health and including a significant increase for the Centers for Disease Control in the fiscal year 2014 Consolidated Appropriations Act, which came after several years of cuts.

As you work to develop a fiscal year 2015 Labor, HHS bill, I urge you to build on this much-needed increase and ensure adequate funding for prevention and preparedness programs at the CDC and other public health agencies.

Eighty-five percent of the CDC's annual budget flows to your States and districts in the form of grants and contracts to State and local public health departments and community partners to conduct critical public health and prevention activities that every American relies on. This includes protecting us from infectious disease by combating healthcare-associated infections, delivering immunizations, and ensuring preparedness for events such as a terrorist attack or a natural disaster.

Preparedness grants helped save lives during the Boston Marathon bombings; tornadoes in Kentucky, Missouri, and Oklahoma; and Hurricane Sandy. Reduced funding for these grants means fewer States will have the core capabilities they need to save lives when disaster strikes.

A sustained investment in public health and prevention is also essential to reduce high rates of disease and improve health in the United States. The CDC and its grantees are working to help give Americans the information they need to adopt the healthy lifestyles that will reduce the chronic disease burden on our healthcare system.

In 2012, we spent roughly 75 percent of our Nation's annual $2,800,000,000,000 healthcare bill on treating preventable chronic diseases. Long-term healthcare spending at these levels is unsustainable for our economy and our budget.

There is a growing evidence base that demonstrates that the majority of chronic disease is preventable by addressing common risk factors. We have begun to see signs of success, with childhood obesity rates declining in cities and States that were among the first

to adopt a comprehensive approach to obesity prevention. It is essential to engage not only healthcare systems, but sectors such as education, housing, transportation, planning, faith-based institutions, and business if we want to transform communities to make the healthy choice the easy choice for families and prevent illness in the first place.

We were pleased that last year Congress made important new investments in community prevention, including the Partnerships to Improve Community Health grants that will help bring that knowledge to scale and continue our efforts to transform our healthcare system to one that values prevention and wellness. We urge the committee to build on those investments in the fiscal year 2015 bill.

I also want to thank you for allocating the Prevention and Public Health Fund and urge you to do so again in fiscal year 2015. To date, the fund has made investments in every State to support State and local efforts to transform and revitalize communities, build lab capacity, train the public health workforce, and help control the obesity epidemic.

Just one example of the fund at work is the Tips from Former Smokers campaign, featuring very graphic messages from former smokers about the health consequences of smoking. The Tips campaign has already inspired more than 1.6 million people to try to quit, and more than 100,000 have quit for good. This will translate to immediate improvements in health and reduced health costs.

Finally, I want to join my colleagues in mentioning prescription drug abuse, which is a growing public health crisis. Overdose deaths involving prescription painkillers have quadrupled since 1999 and now outnumber deaths from all illicit drugs, including heroin and cocaine combined.

This is a multifaceted problem, and the CDC, SAMHSA, NIH, and a range of other agencies have a role to play in finding the solution. We urge you to provide the funding to help address the drivers of the epidemic and to ensure that patients with addiction have access to the treatment they need to turn their lives around.

Tomorrow, the Robert Wood Johnson Foundation will release their 2014 county health rankings, and if past years are any indication, it will serve as another sobering reminder that an American's zip code is a strong predictor of whether or not they have the opportunity to lead a healthy life. It does not have to be this way.

Meeting these twin challenges of protecting the American people from natural and manmade threats and preventing disease can only occur with continued support for CDC.

Thank you again.

[The information follows:]

Written Statement of Rebecca Salay
Director of Government Relations, Trust for America's Health
House Appropriations Subcommittee on Labor, Health & Human Services, Education and Related Agencies

I'm Rebecca Salay, Director of Government Relations for Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by working to make disease prevention a national priority. We do not accept government funding, nor do we represent anyone who does. As this subcommittee works to develop a FY2015 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to ensure adequate funding for public health prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and other public health agencies.

After several years of cuts, Congress included a significant increase to CDC in the FY2014 Consolidated Appropriations Act, and we thank you for recognizing the importance of public health. Eighty-five percent of the CDC's annual budget flows to your states and districts in the form of grants and contracts to state and local public health departments, and community partners, to conduct critical public health and prevention activities that every American relies on, such as protecting us from infectious disease by combating healthcare-associated infections, delivering immunizations, ensuring preparedness, and conducting nonstop surveillance.

The CDC and its grantees across the country are working to help give Americans the information they need to adopt the healthy lifestyles that will reduce the chronic disease burden on our health care system. In 2012, we spent roughly 75 percent of our nation's annual $2.8 trillion health care bill on treating preventable chronic diseases. Long-term health care spending at these levels is unsustainable for our economy and our federal budget.

There is a growing evidence base that demonstrates that the majority of chronic disease is preventable by addressing common risk factors. We have begun to see signs of success, with

childhood obesity rates declining in cities and states that were among the first to adopt a comprehensive approach to obesity prevention. We must bring that knowledge to scale, so that Americans across the country have the opportunity to lead healthier lives. We were pleased that last year Congress made important new investments in community prevention that will help continue our efforts to transform our health care system to one that values prevention and wellness, and we urge the Committee to build on those investments in the FY2015 bill.

Tomorrow, the Robert Wood Johnson Foundation will release their 2014 County Health Rankings, and if past years are any indication, it will serve as another sobering reminder that an American's zip code is a strong predictor of whether or not they have the opportunity to lead a healthy life. Meeting these twin challenges of protecting the American people from natural and man-made threats and preventing disease can only occur with continued support for CDC.

Centers for Disease Control and Prevention (CDC)

From FY 2010 to 2013, the CDC saw its budget authority cut by 18 percent. We were pleased that the FY2014 Omnibus Appropriations measure provided CDC with an increase of more than $550 million, including $373 million from the Prevention and Public Health Fund, resulting in a nearly $175 million increase for chronic disease programs. For perspective, however, that increase simply brought CDC funding back to FY2013 levels. Scarce resources means CDC will be forced to make extremely difficult, sometimes life and death choices. **We urge the Committee to maintain adequate CDC funding levels in FY 2015.**

The Prevention and Public Health Fund (PPHF)

TFAH was pleased to see Congress exercise its authority to allocate the Prevention and Public Health Fund in FY 2014, and we urge this committee to do so again in the FY 2015 appropriations bill. To date, the Fund had made investments in every state to support

state and local efforts to transform and revitalize communities, build epidemiology and laboratory capacity to track and respond to disease outbreaks, address healthcare associated infections, train the nation's public health and health workforce, prevent the spread of HIV, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)

Our nation's doctors and hospitals are our trusted front line when illness appears, but we must continue to engage not only health systems but sectors such as education, housing, business and planning to transform communities to make the healthy choice the easy choice and prevent illness in the first place. The Chronic Disease Center has made progress in moving away from the traditional categorical approach to funding disease prevention and toward more coordinated, cross-cutting strategies. While we were disappointed at the premature termination of the Community Transformation Grants program, TFAH appreciates the new investments in community prevention made in FY2014. **We hope the Committee restores funding for the Chronic Disease Center to FY 2010 levels ($1.167 billion), building upon FY2014 investments in diabetes, heart disease and stroke, the Partnerships to Improve Community Health initiative, the Racial and Ethnic Approaches to Community Health program and the Preventive Health and Health Services Block Grant program.** For the block grant, TFAH calls upon the Committee to promote its use to modernize our public health system by supporting health department accreditation and other efforts to ensure the nation's health departments can deliver foundational public health capabilities to all Americans.

National Center for Environmental Health (NCEH)

Critical programs conducted at the CDC National Center for Environmental Health support our chronic disease prevention and public health preparedness efforts. Yet it remains

one of the most critically underfunded parts of CDC. **We recommended that you fund NCEH at FY2010 levels ($181.004 million) in FY2015** to continue to rebuild the lead control program, grow our National Environmental Public Health Tracking Network, and pursue other priorities.

Public Health Emergency Preparedness Grants

The Public Health Emergency Preparedness (PHEP) Grants, administered by CDC, is the only federal program that supports the work of health departments to prepare for all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks. The grants fund nearly 4,000 state and local public health staff positions, and support 15 core capabilities including public health laboratory testing, surveillance and epidemiology, community resilience, countermeasures and mitigation, and more. These funds are used for everyday preparedness activities, such as monitoring public health threats, and have been integral in expanding to respond to full-scale disasters such as Hurricane Sandy, the fungal meningitis outbreak, and the West Nile Virus outbreak in Texas. **TFAH recommends $670 million for the Public Health Emergency Preparedness Cooperative Agreements in FY2015** to help states and localities restore some of the core capabilities lost due to significant cuts to the program.

Hospital Preparedness Program

The Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response (ASPR), provides funding and technical assistance to prepare the health system to respond to and recover from a disaster. The program, which began in response to 9/11, has evolved from one focused on equipment and supplies held by individual hospitals in response to a terrorist event, to a system-wide, all-hazards approach. The new HPP is building the capacity of healthcare coalitions - regional collaborations between healthcare organizations, providers, emergency managers, public sector agencies, and other private partners - to meet the

disaster healthcare needs of communities. Through the coalition planning process, facilities are learning to leverage resources, such as developing interoperable communications systems, tracking beds, and writing contracts to share assets.

HPP helped a prepared healthcare system save lives during recent events, including the Boston Marathon bombings and tornadoes in Kentucky and Joplin, MO. HPP appropriations have decreased from $426 million in FY10 to $255 million in FY2014, including a one third cut in the FY2014 omnibus. **TFAH recommends $300 million for FY2015 for HPP, an incremental step to rebuild the program.** The significant reduction in FY14 will likely result in fewer staff, fewer coalitions and less of the nation prepared for disasters.

Combatting Prescription Drug Abuse

Prescription drug abuse is a growing public health crisis. Overdose deaths involving prescription painkillers have quadrupled since 1999 and now outnumber deaths from all illicit drugs, including heroin and cocaine, combined. **TFAH recommends a $15.6 million increase to the CDC Injury Center's Injury Prevention Activities line** to enable the CDC to work with additional states with a high burden of prescription drug abuse to help address the main drivers of the epidemic of prescription drug overdoses—high-risk prescribing and high-risk patients.

Conclusion

Investing in disease prevention is the most effective, common-sense way to improve health and address our long-term deficit. Hundreds of billions of dollars are spent each year to pay for health care services once patients develop an acute illness, injury, or chronic disease. A sustained investment in public health and prevention is essential to reduce high rates of disease and improve health in the United States.

Mr. KINGSTON. Thank you very much, and welcome back to the Hill.

Ms. DeLauro, you may have some—you might want to cross-examine this one?

Ms. DELAURO. No, no. Thank you very, very much. Thank you for your advocacy, but more your dedication and your commitment to these issues, which has been longstanding. And it has been my pleasure to have the opportunity to work with you as a colleague. Thank you very much.

Mr. KINGSTON. But I need to ask. Has the health in Connecticut improved? I just want to know. I am sure it has, between the two of you.

Ms. SALAY. We are trying.

Ms. DELAURO. We try. We continue to try, and it is really with great pride do I sit here and listen to Rebecca Salay talk the way she does and with the work that she is engaged in. Just a moment—she started on Capitol Hill as an intern and moved to legislative director, worked in the White House, came back to the Hill, and now is running—working in an organization that is doing so much for our country. So we are grateful.

Mr. KINGSTON. So if I am hearing you correctly, she left politics and finally made something out of herself. [Laughter.]

Ms. DELAURO. That is right. She took the right road.

Mr. KINGSTON. I do want to say that an interesting statistic that I got from the CDC recently is that the I think the European—the rate of smokers in Europe is about 40 percent, and in America, it is 20 percent. But among physicians, it is 2 percent, which is kind of a warning.

Ms. DELAURO. Well, Mr. Chairman, the number sticks in my mind, 480,000 people die every year from a tobacco-related illness. That is pretty staggering——

Mr. KINGSTON. Yes.

Ms. DELAURO [continuing]. When we think of what we can do by way of prevention.

Mr. KINGSTON. Well, the 20 percent was a great decline in the last 10 years, and I just thought——

Ms. Lee. Thank you very much. What is that?

Ms. LEE. We need additional taxes on tobacco.

Mr. KINGSTON. I see that Governor Kasich has proposed that in Ohio. I was reading that.

Ms. LEE. Yes, I think it would save many more lives.

Mr. KINGSTON. Next, Dr. Beverly Tatum, president of Spelman College. We are glad to have you here.

TUESDAY, MARCH 25, 2014.

SPELMAN COLLEGE ON BEHALF OF UNCF

WITNESS

BEVERLY DANIEL TATUM, PH.D., PRESIDENT, SPELMAN COLLEGE ON BEHALF OF UNCF

Ms. TATUM. Thank you, Chairman Kingston.

And to Ranking Member DeLauro and Representative Lee, I am pleased to have this opportunity.

I am Dr. Beverly Daniel Tatum, president of Spelman College in Atlanta, Georgia. And Spelman was founded in 1881. It is the global leader in the education of women of African descent and a historically black college.

Since 2008, Spelman College has averaged a 6-year graduation rate of 77 percent, one of the highest of the 105 historically black colleges and universities and substantially above the national average for all institutions of 59 percent.

Spelman College is one 37 private historically black colleges and universities that are members of the United Negro College Fund, which I am representing today. UNCF is the Nation's largest higher education organization serving students of color, perhaps best known by the iconic motto, "A mind is a terrible thing to waste."

HBCUs represent approximately 4 percent of all 4-year colleges and universities but enroll 9 percent of all African-American college students, confers 16 percent of their bachelor's degrees, and generate 27 percent of the science, technology, and engineering, mathematics bachelor's degrees awarded to African Americans. We do this while serving students with greater need.

More than 70 percent of students who attend HBCUs are low-income students who depend on Federal Pell grants for their education, a substantially greater share than the 43 percent of students at all other 4-year colleges and universities. At the same time, total cost of attendance at HBCUs is 30 percent lower on average than other 4-year institutions.

I would like to thank all three of you on this subcommittee for playing leadership roles in restoring some of the vital Federal resources to HBCUs and the students we serve in the fiscal year 2014 budget. UNCF appreciates you providing a maximum Pell award of $5,730, restoring sequestration cuts to other student aid programs, and restoring two-thirds of the sequestration cuts to the Title III HBCU programs.

Looking to fiscal year 2015, a national strategy to produce more college graduates, boost our economy, and enhance global competitiveness must include greater investment in HBCUs. On behalf of the UNCF institutions and all HBCUs, I urge the subcommittee to support our highest priority programs listed in attachment to my testimony.

In particular, I urge you to appropriate $267,000,000 in discretionary dollars and $85,000,000 in mandatory dollars for the Title III, Strengthening Historically Black Colleges and Universities Program. These are formula funds awarded to HBCUs for operational support and essential academic services.

I would like to note that during the 2007–2012 grant cycle, Spelman College received and expended more than $11,000,000 in Title III funding. We used these funds to include infrastructure, campus infrastructure, upgrades in technology, for facilities, classrooms, labs, and centers. Title III assisted with the establishment of the SpelBots, Spelman's robotic team, a winning robotics initiative.

Additional examples of the achievements that critical Title III funding has supported at Spelman are included as an attachment to my testimony. Please reinvest in this program and restore the $43,000,000 cut from the program since fiscal year 2010.

The HBCU Capital Financing Program finances low-risk Federal loans to help HBCUs, especially private institutions, improve facilities, infrastructure, and technology. I urge you to increase the appropriation for loan subsidies to $25,000,000, which would leverage $390,000,000 in annual loans to meet the infrastructure needs of our institutions.

Without Pell grants, most HBCU students could not pay for the college education they need. I urge you to fund a $5,830 maximum Pell award to help our students persist and complete college.

In addition, I encourage you to reinstate summer Pell grants so students can earn their college degrees faster and at a lower cost. UNCF also strongly supports the President's fiscal year 2015 request of $75,000,000 for college success grants for minority-serving institutions.

Finally, I urge you to restore the health profession's training for diversity programs to fiscal year 2012 levels and ask that you expand the National Institute on Minority Health and Health Disparities to $283,000,000.

We also urge you to approve the proposed college opportunity and graduation bonuses, which would reward institutions that enroll and graduate large numbers of low-income students. We recommend that this proposal be amended, however, to take into consideration both the numbers and percentages of low-income students graduating from institutions, given that some HBCUs have smaller enrollment.

Mr. Chairman and members of the subcommittee, you have the power to increase Federal resources for operating support, student assistance, best practices, and innovation so that HBCUs and the students we serve can thrive.

Thank you for your support. That concludes my testimony. The rest of my remarks I would like to have submitted for the record.

[The information follows:]

Public Witness Hearing on Fiscal Year 2015 Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
U.S. House of Representatives
Tuesday, March 25, 2014

Testimony of Dr. Beverly Daniel Tatum, President, Spelman College
On Behalf of the UNCF (United Negro College Fund)
RE: FY 2015 Budget Priorities for
Historically Black Colleges and Universities

Introduction

Good morning, Chairman Kingston, Ranking Member DeLauro and Members of the Subcommittee. I am Dr. Beverly Daniel Tatum, President of Spelman College in Atlanta, Georgia. Mr. Chairman, it is good to see you again after our meeting last year. Founded in 1881, Spelman College is a global leader in the education of women of African descent and a Historically Black College. Since 2008 Spelman College has averaged a 6-year graduation rate of 77 percent – one of the highest of the 105 Historically Black Colleges and Universities and substantially above the national average of 59 percent.

Spelman College is one of the 37 private Historically Black Colleges and Universities (HBCUs) that are members of the United Negro College Fund (UNCF), which I am representing today. UNCF is the nation's largest higher education organization serving students of color, perhaps best known by the iconic motto – "A mind is a terrible thing to waste®."

In its 70-year history, UNCF has raised more than $4 billion in scholarship aid to help more than 400,000 students of color attend HBCUs and 900 other colleges and universities

across the country to obtain the education they need to excel in the 21st century economy. UNCF's largest scholarship is the Gates Millennium Scholarship offered to high-achieving, low-income African American, American Indian/Alaska Native, Asian Pacific Islander and Hispanic American students. Mr. Chairman, UNCF has awarded Gates Millennium Scholarships totaling $48 million to help 840 students from Georgia earn college degrees, including 45 Gates Scholars at Spelman College. We have awarded over $310 million to 6,200 Gates Scholars from the 10 states the Subcommittee represents.

HBCU Value Proposition

UNCF's core mission, however, remains its partnership with the nation's 37 private HBCUs. The money raised by UNCF has become even more important today as HBCUs have suffered from a "perfect storm" of federal disinvestments since 2011. Limitations on Pell Grant eligibility requirements, sequestration cuts to the Title III HBCU Program and Parent PLUS Loan reductions have resulted in a loss of more than $250 million in federal support. Despite these challenges, HBCUs provide enormous value for students and the nation. HBCUs represent approximately 4 percent of all four-year colleges and universities; enroll 9 percent of all African American college students; confer 16 percent of bachelor's degrees awarded to African Americans; and generate 27 percent of the STEM bachelor's degrees awarded to African Americans. Moreover, HBCUs accomplish this while serving students with greater need: more than 70 percent of students who attend HBCUs are low-income students who depend on federal Pell Grants for their education, a substantially greater share than the 43 percent of students at all other four-year colleges and universities. At the same time, total cost of attendance at HBCUs is 30 percent lower, on average, than other four-year institutions.

FY 2014 Appropriations

I would like to thank the Subcommittee and, in particular, Chairman Kingston, Ranking Member DeLauro and Congresswoman Lee, for playing leadership roles in restoring some of the vital federal resources to HBCUs and the students we serve in the FY 2014 budget. UNCF appreciates you providing a maximum Pell award of $5,730, restoring sequestration cuts to other student aid programs, and restoring two-thirds of the sequestration cuts to the Title III HBCU Program.

FY 2015 Appropriations Priorities

Looking to FY 2015, a national strategy to produce more college graduates, boost our economy and enhance global competitiveness must include greater investment in HBCUs. On behalf of the UNCF institutions and all HBCUs, I urge the Subcommittee to support our highest priority programs listed in the attachment to my testimony. In particular,

- I urge you to appropriate $267 million in discretionary dollars and $85 million in mandatory dollars for the **Title III - Strengthening Historically Black Colleges and Universities Program**. These are formula funds awarded to HBCUs for operational support and essential academic services. Let me note that during the 2007-2012 grant cycle, Spelman College received and expended more than $11 million in Title III funding. Spelman has enhanced its campus infrastructure to include upgrades in technology to facilities, classrooms, labs and centers. Title III assisted with the establishment of the SpelBots (Spelman's Robotic Team) a winning robotics initiative. Additional examples of the achievements that critical Title III funding has supported at Spelman are included as an attachment to my testimony. Please reinvest in this program and restore the $43 million cut from the program since FY 2010.

- The **HBCU Capital Financing Program** finances low-risk federal loans to help HBCUs, especially private institutions, improve facilities, infrastructure and technology. Investing in capital projects not only enhances the educational environment for students but also reinvigorates our communities and provides much needed jobs. I urge you to increase the appropriation for loan subsidies to $25 million, which would leverage $390 million in annual loans to meet the infrastructure needs of our institutions.
- Without **Pell Grants**, most HBCU students could not pay for the college education that is essential in today's economy. I urge you to fund a $5,830 maximum Pell award to help our students persist and complete college. In addition, I encourage you to reinstate "summer" Pell Grants so students can earn their college degrees faster and at a lower cost.
- UNCF also strongly supports the President's FY 2015 request of $75 Million for **College Success Grants for Minority-Serving Institutions.** These competitive grants would help Minority-Serving Institutions launch new innovations and best practices to improve student outcomes. I urge you to fully fund this important initiative.
- I urge you to approve the proposed **College Opportunity and Graduation Bonuses**, which would reward institutions that enroll and graduate large numbers of low-income students. UNCF recommends that this proposal be amended to take into consideration both the numbers <u>and</u> percentages of low-income students graduating from institutions, given that some HBCUs have smaller enrollments.
- Finally, I urge you to restore the **Health Professions Training for Diversity** programs to FY 2012 levels and ask that you expand the **National Institute on Minority Health and**

Health Disparities to $283 million to improve diversity in the workforce and research funding for minority populations.

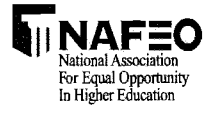
Mr. Chairman, Ranking Member DeLauro and members of this Subcommittee – you have the power to increase federal resources for operating support, student assistance, best practices and innovations so that HBCUs can thrive in years to come. Or, you can adhere to the status quo and allow our institutions to merely survive.

UNCF does not accept the status quo. We are accelerating our fundraising efforts, investing in capacity building at our member institutions, building new partnerships and leveraging our resources to enhance educational opportunities for minority students. In fact, UNCF has updated its motto to recognize education is an investment in better futures for everyone. We believe that, "A mind is a terrible thing to waste, but a wonderful thing to invest in." Please help us invest in our youth, in our HBCUs, and most importantly, in our country so that millions more low-income, minority students can graduate from college and lead our country to heights we have yet to imagine.

Thank you for the opportunity to testify today. I would be pleased to answer any questions.

Attachments:

- HBCU Coalition FY 2015 Appropriations Priorities
- UNCF Member Institutions
- Spelman College Title III Accomplishments
- Biography of Dr. Beverly Daniel Tatum
- Witness Disclosure Form



HBCU COALITION FY 2015 BUDGET PRIORITIES FOR THE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS SUBCOMMITTEE

DEPARTMENT/ AGENCY PROGRAM	FY 2012 APPROPRIATION	FY 2013 FULL YEAR CONTINUING RESOLUTION (W/SEQUESTER CUT)	FY 2014 CONSOLIDATED APPROPRIATIONS ACT (P.L. 113-76)	FY 2015 PRESIDENT'S REQUEST	FY 2015 HBCU COALITION REQUEST
DEPARTMENT OF EDUCATION					
Pell Grant (Maximum Award)	$41.6 billion ($5,550)	$35.3 billion ($5,645)	$22.8 billion ($5,730)	$22.8 billion[1] ($5,830)	$22.8 billion ($5,830)
Supplemental Educational Opportunity Grants	$734.6 million	$697.9 million	$733.1 million	$733.1 million	$757 million
Federal Work Study	$976.7 million	$927.9 million	$974.7 million	$974.7 million	$1.13 billion
Title II, Teacher Quality Partnership Grants	$42.8 million	$40.7 million	$40.6 million	$0	$43 million
Strengthening Institutions Title III, Part A	$80.6 million	$76.6 million	$79.1 million	$79.1 million	$81 million
Strengthening Historically Black Colleges Title III, Part B, Section 323 Discretionary Funding Mandatory Funding	 $228.4 million $85 million (mandatory)	 $216 million $80.7 million[2] (mandatory subject to sequestration)	 $223.8 million $78.9 million[3] (mandatory subject to sequestration)	 $223.8 million $85 million (mandatory)	 $267 million $85 million (mandatory)

[1] The President's FY 2015 discretionary budget request of $22.8 billion for Pell Grants would support the scheduled increase in current law for the maximum Pell award by an estimated $100, from $5,730 in award year 2014-2015, to $5,830 in award year 2015-2016, while also fully funding the program through award year 2016-2017.

[2] Reflects the 5.2 percent sequester that went into effect on March 2013, pursuant to the Budget Control Act of 2011.

[3] Reflects the 7.2 percent sequester that went into effect on October 1, 2013, pursuant to the Budget Control Act of 2011.

HBCU COALITION FY 2015 BUDGET PRIORITIES FOR THE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS SUBCOMMITTEE

DEPARTMENT/ AGENCY PROGRAM	FY 2012 APPROPRIATION	FY 2013 FULL YEAR CONTINUING RESOLUTION (W/SEQUESTER CUT)	FY 2014 CONSOLIDATED APPROPRIATIONS ACT (P.L. 113-76)	FY 2015 PRESIDENT'S REQUEST	FY 2015 HBCU COALITION REQUEST
Title III, Part B, Section 326	$59 million	$56.1 million	$57.9 million	$57.9 million	$61 million
Title III, Part C, Endowment Grant	$0	$0	$0	$0	$25 million
Title VII, Masters Degree Programs at HBCUs and PBIs	$11.5 million (Mandatory)	$10.9 million[4] (Mandatory subject to sequestration)	$10.7 million[5] (Mandatory subject to sequestration)	$0	$11.5 million (Mandatory)
Strengthening Predominantly Black Institutions (PBIs)	$9.3 million (discretionary) $15 million (mandatory)	$8.8 million (discretionary) $14.2 million[6] (mandatory subject to sequestration)	$9.1 million (discretionary) $13.9 million[7] (mandatory subject to sequestration)	$9.1 million (discretionary) $15 million (mandatory)	$11 million (discretionary) $15 million (mandatory)
Minority Science and Engineering Improvement Program (MSEIP)	$9.48 million	$8.93 million	$9 million	$9 million	$9.5 million
Title VI, International Education (domestic/overseas)	$74.1 million	$70.4 million	$72.2 million	$76.2 million	$82 million
First in the World Initiative	$0	$0	$75 million	$100 million	$100 million
Set-aside for Minority-Serving Institutions	N/A	N/A	Up to $20 million	$0	$0[8]

[4] Reflects the 5.2 percent sequester that went into effect on March 2013, pursuant to the Budget Control Act of 2011.

[5] Reflects the 7.2 percent sequester that went into effect on October 1, 2013, pursuant to the Budget Control Act of 2011.

[6] Reflects the 5.2 percent sequester that went into effect on March 2013, pursuant to the Budget Control Act of 2011.

[7] Reflects the 7.2 percent sequester that went into effect on October 1, 2013, pursuant to the Budget Control Act of 2011.

[8] In the FY 2015 request, this set aside is replaced by College Success Grants, for which $75 million is proposed.

HBCU COALITION FY 2015 BUDGET PRIORITIES FOR THE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS SUBCOMMITTEE

DEPARTMENT/ AGENCY PROGRAM	FY 2012 APPROPRIATION	FY 2013 FULL YEAR CONTINUING RESOLUTION (W/SEQUESTER CUT)	FY 2014 CONSOLIDATED APPROPRIATIONS ACT (P.L. 113-76)	FY 2015 PRESIDENT'S REQUEST	FY 2015 HBCU COALITION REQUEST
College Success Grants				$75 million	$75 million
TRIO	$839.9 million	$797.9 million	$838.2 million	$838.2 million	$890 million
GEAR UP	$302.2 million	$287.1 million	$301.6 million	$301.6 million	$323 million
College Opportunity and Graduation Bonuses				$647 million (Mandatory)	$647 million (Mandatory)
Howard University	$234.1 million	$222.4 million	$221.8 million	$221.8 million	$234.5 million
HBCU Capital Financing Loan Subsidies (New Loan Volume)	$20.5 million ($320 million)	$19.5 million[9] ($304 million)	$19.4 million[10] ($304 million)	$19.4 million ($304 million)	$25 million ($390 million)
Five-Fifths Agenda for America Initiative				$0	$50 million
DEPARTMENT OF HEALTH AND HUMAN SERVICES					
Health Professions for Diversity/HRSA	$85.1 million	$80.8 million	$82.6 million	$66.6 million	$85.1 million
Minority Centers of Excellence	$22.9 million	$21.8 million	$21.7 million	$21.7 million	$23 million
Health Careers Opportunity Program	$15 million	$14.3 million	$14.2 million	$0	$15 million

[9] Reflects the 5.2 percent sequester that went into effect on March 2013, pursuant to the Budget Control Act of 2011.

[10] Appropriations for this program are made available for two years, rather than for one year, through September 30, 2015.

HBCU COALITION FY 2015 BUDGET PRIORITIES FOR THE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS SUBCOMMITTEE

DEPARTMENT/ AGENCY PROGRAM	FY 2012 APPROPRIATION	FY 2013 FULL YEAR CONTINUING RESOLUTION (W/SEQUESTER CUT)	FY 2014 CONSOLIDATED APPROPRIATIONS ACT (P.L. 113-76)	FY 2015 PRESIDENT'S REQUEST	FY 2015 HBCU COALITION REQUEST
Scholarships for Disadvantaged Students	$47.5 million	$45.4 million	$45 million	$45 million	$47.5 million
Faculty Loan Repayment	$1.24 million	$1.18 million	$1.19 million	$1.19 million	$1.25 million
NIH National Institute on Minority Health Disparities	$276.9 million	$265.3 million	$268.3 million	$267.9 million	$283.3 million

UNCF
A mind is a terrible thing to waste

UNCF MEMBER INSTITUTIONS

Allen University
Columbia, SC 29204

Benedict College
Columbia, SC 29204

Bennett College
Greensboro, NC 27401

Bethune-Cookman University
Daytona Beach, FL 32114

Claflin University
Orangeburg, SC 29115

Clark Atlanta University
Atlanta, GA 30314

Dillard University
New Orleans, LA 70122

Edward Waters College
Jacksonville, FL 32209

Fisk University
Nashville, TN 37208

Florida Memorial University
Miami, FL 33054

Huston-Tillotson University
Austin TX 78702

Interdenominational Theological Center
Atlanta, GA 30314

Jarvis Christian College
Hawkins, TX 75765

Johnson C. Smith University
Charlotte, NC 28216

Lane College
Jackson, TN 38301

LeMoyne-Owen College
Memphis, TN 38126

Livingstone College
Salisbury, NC 28144

Miles College
Fairfield, AL 35064

Morehouse College
Atlanta, GA 30314

Morris College
Sumter, SC 29150

Oakwood University
Huntsville, AL 35896

Paine College
Augusta, GA 30901

Philander Smith College
Little Rock, AR 72202

Rust College
Holly Springs, MS 38635

Saint Augustine's University
Raleigh, NC 27610

Shaw University
Raleigh, NC 27601

Spelman College
Atlanta, GA 30314

Stillman College
Tuscaloosa, AL 35401

Talladega College
Talladega, AL 35160

UNCF MEMBER INSTITUTIONS

Texas College
Tyler, TX 75712

Tougaloo College
Tougaloo, MS 39174

Tuskegee University
Tuskegee, AL 36088

Virginia Union University
Richmond, VA 23220

Voorhees College
Denmark, SC 29042

Wilberforce University
Wilberforce, OH 45384

Wiley College
Marshall, TX 75670

Xavier University
New Orleans, LA 70125

Spelman College

Highlights: Title III, Part B, Sec. 323 – Strengthening Historically Black Colleges and Universities Program

Spelman College is the oldest historically black college for women. Located in Atlanta, Georgia, Spelman was founded in 1881 as the Atlanta Baptist Female Seminary. The College maintains a student population of approximately 2,000 from 45 U.S. states and 13 countries, and since 2008 has had an average 6-yr graduation rate of 77 percent.

Title III – Strengthening Historically Black Colleges and Universities funding plays a critical role in obtaining resources that provide students and faculty with unparalleled opportunities for educational enrichment and advancement. In the 2007-2012 grant cycle, Spelman College expended more than $11 million in Title III funds. Those resources were expended on a number or projects with wide-ranging effects on student life, faculty engagement, and facility improvement.

Title III funding supports and enhances institutional efforts in four critical areas: Academic Quality, Student Services Outcomes, Institutional Management and Fiscal Stability. Our advancements in these key areas are reflected in key indicators related to enrollment, retention, graduation and fiscal stability.

- Title III funding undergirds 100 percent of the Foundational Priorities of the College's Strategic Plan, enhancing academic rigor in new student orientation, freshman-year and sophomore-year experiences.
- The College's retention rate is 90 percent. The average five-year (2007-2011) second-year retention rate is 87 percent. Title III funds continue to assist the institution with providing supportive programs that ensure Spelman's first and second year students successfully progress to junior status.
- The College's six-year graduation rate has ranged from a high of 83 percent to a low of 73 percent.. The average six-year (2001-2006) cohort rate is 77 percent.
- Forty-nine Global STEM students have conducted STEM research abroad since 2011.
- 48 labs and 22 classrooms upgraded with state-of-the-art technology.
- Between 2008-2012, Spelman had 722 students who were admitted to and attended graduate or professional degree programs in disciplines in which African Americans are underrepresented.

Select Examples of Title III Activities that Support our Success

- A campus classroom was transformed into a data analysis hub, with 16 new workstations installed. More than 90 percent of students reported that their interest in and skills related to data analysis improved as a result of their work in this facility.

- The College implemented *DegreeWorks*, an online auditing and advising system that aids students in proactively creating and fulfilling their individual academic plans and assists faculty advisors in providing effective support.

- Spelman's Education Studies Program enlarged its interdisciplinary course offerings through the addition of a new course entitled "History and Philosophy of African American Education."

- Creation and implementation of the Student Success Center, which provides a centralized location for student support services.

- Spelman's Department of Computer and Information Science (CIS) achieved international recognition for the accomplishments of its graduates and for its award-winning robotics initiative. The SpelBots participated in the NSF Education Technology Senate showcase in November 2009.

These accomplishments serve as evidence of the important role that resources from the Strengthening Historically Black Colleges and Universities program play at Spelman and on HBCU campuses across the nation.

UNCF
A mind is a terrible thing to waste®

BIOGRAPHICAL SKETCH
BEVERLY DANIEL TATUM, PH.D.

A 2013 recipient of the Carnegie Academic Leadership Award, Dr. Beverly Daniel Tatum has served as president of Spelman College since 2002. Her tenure as president has been marked by a period of great innovation and growth. Spelman College, long recognized as the leading educator of women of African descent, is now ranked among the top 100 liberal arts colleges in the nation and is one of the most selective women's colleges in the United States. Overall, scholarship support for Spelman students has tripled since 2002, and opportunities for faculty research and development have expanded significantly. In 2008, the Gordon-Zeto Fund for International Initiatives was established with a gift of $17,000,000, creating more opportunities for faculty and student travel and increased funding for international students. Alumnae support of the annual fund has also tripled, reaching a record high of 41% in 2011. Campus improvements include the award-winning renovation of four historic buildings and the 2008 completion of a new "green" residence hall, increasing on-campus housing capacity by more than 25% and establishing the campus commitment to environmental sustainability for the 21st century.

In 2012 Dr. Tatum made the bold decision to withdraw from NCAA intercollegiate sports participation, a program serving less than 100 students, in favor of a campus-wide wellness initiative designed to impact the entire student community of 2100. Collectively, these improvements serve as the foundation for *Strengthening the Core: The Strategic Plan for 2015*, which focuses on global engagement, expanded opportunities for undergraduate research and internships, alumnae-student connections, leadership development and service learning linked to an increasingly interdisciplinary curriculum.

An accomplished administrator, Dr. Tatum is widely recognized as a race relations expert and leader in higher education. Her areas of research include racial identity development, and the role of race in the classroom. She is the author of *Can We Talk About Race? And Other Conversations in an Era of School Resegregation* (2007) and *"Why Are All the Black Kids Sitting Together in the Cafeteria?" and Other Conversations about Race* (1997) as well as *Assimilation Blues: Black Families in a White Community* (1987). A Fellow of the American Psychological Association, in 2005 Dr. Tatum was awarded the prestigious Brock International Prize in Education for her innovative leadership in the field.

In addition to her active involvement in the Atlanta community, Dr. Tatum is a member of national non-profit boards including the Institute for International Education, the Carnegie Foundation for the Advancement of Teaching, and Teach for America. Appointed by President Obama, she is a member of the Advisory Board for the White House Initiative on Historically Black Colleges and Universities. She also serves on the Georgia Power corporate board of directors.

She holds a B.A. degree in psychology from Wesleyan University, and M.A. and Ph.D. in clinical psychology from University of Michigan as well as an M.A. in Religious Studies from Hartford Seminary. Prior to her appointment at Spelman, she served as dean and acting president at Mount Holyoke College. President Tatum is married to Dr. Travis Tatum, professor emeritus of education; they are the parents of two adult sons.

Mr. KINGSTON. Without objection.

Dr. Tatum, let me say this, as a Georgian, we are all very proud of Spelman, but not just as a Georgia institution, but what you do internationally and nationally, you have really a great reputation worldwide. And so, I think every Georgian has great pride in you, but it goes well beyond the State line.

Ms. TATUM. Well, thank you very much.

Mr. KINGSTON. I also wanted to ask a little bit about Pell grants. I heard a statistic the other day, and I am looking into it, that in some institutions the graduation rate is as low as 2 percent. I am not sure if that is accurate or not. But one of the big pushbacks we get on Pell grants is what is the graduation rate, and how much is it?

And I know you said that you have a high graduation rate in 6 years. It is amazing that so many schools are now, you know, 6 years is very good compared to some of the others. But can you comment on that, just in a broad way?

Ms. TATUM. Well, I can tell you that the average graduation rate for African Americans is about 35 percent nationally across all kinds of institutions. I am not aware of any UNCF institution that would have a graduation rate as low as 2 percent.

Mr. KINGSTON. These were actually private ones.

Ms. TATUM. I was going to say there are—you know, it is my understanding that many of the for-profit institutions struggle with very low graduation rates. But certainly, in the private UNCF historically black college sector, we know that Pell grants are essential for our students to be able to continue.

Mr. KINGSTON. Yes. Ms. DeLauro.

Ms. DELAURO. Just one comment, and I want to say thank you to you. Thank you for the outstanding job, and this is a committee that has longtime supported the colleges, historically black colleges, et cetera. They make such a contribution.

But the issue that you just raised, Mr. Chairman, I think is one that we ought to really take up very seriously, and that is the for-profit facilities that are taking extraordinary amounts of Pell grant aid and without any accountability, that the whole issue of gainful employment and where we need to go to look at the amount of money that they are siphoning away from the system.

And with regard to veterans, they are particularly, and I will use it frankly, ripping off our veterans, and there is actually no accountability, and they are using Federal money and gimmicks to utilize the Federal money.

And they have been left pretty much on their own all this time, and this committee needs to take a very close, hard look at that.

Thank you.

Mr. KINGSTON. Yes.

Ms. LEE. Thank you very much, Mr. Chairman.

And thank you, good to see you, Dr. Tatum.

Let me just say, first of all, how thankful I am, as a Californian, for your tremendous leadership and also for Spelman College, especially in the last 20 years. Unfortunately, we passed a proposition that ended affirmative action in California, which now the net results, of course, are what we knew it would be, and that is very

few African-American students now are admitted into the California university system.

And thank God for HBCUs because the majority of our students now are going to HBCUs because they—because affirmative action has ended and cannot get in for a variety of reasons, even though they are smart, they are brilliant, and they should be able to get in. But they can't. So HBCUs have been lifesavers for us.

And one of the issues then, one of the problems is there is now a brain drain in California in the African-American community because students don't go back once they graduate. They love Spelman, HBCUs, and they become part of the communities in which the HBCUs are housed.

And so, California, now, first of all, I am thankful for the HBCUs, but the impact of that is the black brain drain is becoming very, very dangerous in California. And so, we are going to have to figure out how to address that long term.

With regard to Spelman, staff members, interns. I have a young lady who is going to shadow me on Thursday from Spelman, and so I just have to say I personally know that the quality of the education and the young women that you actually educate is really—I mean, these are international students. These are students who have a global perspective and who are learned and who are going into the new world in which we live in a way that I am very proud of because I know they are prepared for this new world.

I am concerned, though, about, of course, Pell grants, the Parent PLUS program, the changes in Parent PLUS. The fact that the numbers that you laid out are hopefully restored, the sequester cuts. I am not sure. I have to look at that.

But just wanted to ask you the impact of sequestration on Spelman and HBCUs, and to fully restore those cuts, would that mean the numbers that you have laid out in your testimony should be the allocation that we look for? Should we—some of us may want to do more or try to do more.

Ms. TATUM. Well, we would welcome more. There is no question about that. But the numbers that I indicated in my full testimony do speak to the restoration of sequestration cuts and also are reinvesting in Title III to the levels of fiscal year 2010. Yes——

Ms. LEE. Okay.

Ms. TATUM [continuing]. There have been $43,000,000 cut since 2010.

Ms. LEE. Okay. And what about Parent PLUS, the changes in the Parent PLUS?

Ms. TATUM. So the Parent PLUS loan is a more complicated issue. As you may know, the many—with the change in implementation of Parent PLUS, many students and their families found themselves unable to get loans that they were expecting to be able to get. Parents that had been approved in the past were now being rejected.

The strategy that the Department of Education is using to address that is to encourage parents to appeal. So once a family is rejected, they have the option to appeal. At Spelman, we find that most parents who do appeal are then subsequently approved.

However, you might imagine that it is an extra burden for a family, particularly first-generation families that are not college edu-

cated, to go through the process of applying the first time, be rejected, and then appeal again without knowing for sure whether they will be successful is a challenge. I am aware that at other UNCF schools, though our appeal rate has been pretty high, the success rate has been pretty higher, other UNCF schools have not been as fortunate, perhaps because of different demographics in their population.

That said, it has been quite dramatic, the impact on enrollment. Even in Atlanta, for example, Morehouse College has seen a significant drop in its enrollment as a result of Parent PLUS loans. Clark Atlanta University as well saw a significant. Even at Spelman, we are seeing a decline in our graduation rate over the last 2 or 3 years because students are running out of money and are not able to get the loans, which is really tragic.

There was a time when I could have sat here and said the graduation rate at Spelman was 83 percent. It is now averaging at 77 percent. Last year, it was 73 percent. And that drop can be directly linked to difficulties with Parent PLUS and other forms of financial aid.

Ms. LEE. Thank you very much, Mr. Chairman. And we are going to have to talk about that at the subcommittee level.

The Congressional Black Caucus has mounted a major effort on this, but I think we need to discuss some of the details of that.

Mr. KINGSTON. Because, you know, one of the things that I heard Senator Tom Coburn say today something interesting, but we all know it. He said, you know, one of our tendencies in Washington is when there is a problem to create a new program rather than assess the programs that are out there trying to address it.

And as I listened to you, I think about the TRIO program, National Youth Sports, Upward Bound, and I wonder which ones fit into the graduation rate question? Maybe modifying their mission a little bit in terms of, yes, we will get you into college, but now we have got to get you out of college as well.

Ms. TATUM. Well, one of the things that I would say from my perspective as president of Spelman College, a historically black college for women, is that there are a lot of programs that across the Nation that are focused on college access and entry, but what is most critical to college completion is access to Federal financial aid.

And so, I want to point out that the changes to the Parent PLUS loans have cost HBCUs across the board $150,000,000 in total in terms of lost resources that students and families had that are essential to completion. And there is nothing worse, I think it is important to say, than starting a program, taking on debt, and then not being able to complete.

You know, debt and no degree is the worst possible outcome. So we want to be sure that students who start are able to finish.

Mr. KINGSTON. If you see my friend Dr. Dozier with Savannah State, tell her we missed her in the Savannah St. Patrick's Day parade. She is always a stalwart riding in it.

Ms. TATUM. I will be happy to——

Mr. KINGSTON. I went over to the float, but she was in a different—she was at a seminar giving a really pretty serious speech somewhere. But she was smart because it rained the entire parade.

Ms. TATUM. Well, we are pleased to see more women in these roles. So we thank you for your support.

Mr. KINGSTON. Well, she testified for our committee last year.

Ms. TATUM. Thank you for this opportunity.

Mr. KINGSTON. Well, thank you.

And our last witness, unless we have missed anybody, is Pam Wells with Wells Wonder World. And we certainly appreciate your patience.

TUESDAY, MARCH 25, 2014.

WELLS WONDER WORLD

WITNESS

PAM WELLS, WELLS WONDER WORLD

Ms. WELLS. Chairman Kingston, Representative DeLauro, thank you for the opportunity to testify before you today in your investment in early care and education.

I am the owner of Wells Wonder World, a licensed group family childcare home in Hudson Falls, New York, which is about an hour north of Albany. I am also the president of Local 100A CSEA/VOICE, a union of organized independent childcare providers, including 20,000 outside of New York City.

My colleagues and I work out of our homes to provide high-quality early learning and care for infants, toddlers, and young children from birth through age 12. Every day, my childcare colleagues and I see how invaluable childcare assistance through the Childcare and Development Block Grants, the CCDBG, is to families struggling to make ends meet. Without it, many parents would not be able to afford childcare at all and could not go to work.

I respectfully urge you to increase the CCDBG funding by $807,000,000 above its current level as you prepare the fiscal year 2015 budget. A substantial increase is essential for the following three key reasons.

First, to maintain the number of children cared for with Federal childcare assistance. Second, to improve the quality of childcare and prepare for new requirements included in expected CCDBG regulations or reauthorization. And third, to improve childcare provider payment rates.

I began working as a childcare provider 17 years ago when I became a licensed family childcare provider in Hudson Falls, New York. I was a single mother working with three young boys and could not find or afford high-quality childcare. I always enjoyed working with children and decided to operate my own childcare program, make it affordable, and provide high-quality care.

However, some of the hardest things I have had to do is stop providing care to a family that can no longer afford it and turn away parents whose income is just slightly above the eligibility level set by the State. I want to help every family, but not all children who are eligible for assistance through this program receive it. Why? Because there is not enough funding.

Currently, only one in six eligible children receive a subsidy. It is essential to maintain the number of children served. Unfortu-

nately, fewer and fewer eligible children are served by Federal childcare assistance. Nationwide? 263,000 fewer children received assistance in 2012 than in 2006. In fiscal year 2012, New York was not able to help 8,100 children from the prior year after losing $325,000,000 in Federal childcare assistance, even though my State put in more money than the required maintenance of effort to fill the gap.

Without a substantial increase in fiscal year 2015, 74,000 children could lose childcare assistance. We need to do better in order to serve the children of New York and our Nation.

Increased funding is essential to improve quality and prepare for new requirements. We believe that draft CCDBG regulations in S. 1086 make important changes. We are concerned, though, that without significant increases in CCDBG funding, New York and other States will be forced to redirect funds that currently provide subsidies for poor children to fulfill new requirements.

Without sufficient additional funding, States will likely further limit the number of families able to access childcare subsidy. Many families will likely have to turn to lower quality care because it is all they can afford. Sacrificing access to affordable childcare will not help our shared goal of improving quality in childcare.

Provider payment rates, reimbursing childcare provider at reasonable rates is essential to cultivating and sustaining a system of high-quality childcare programs. I am proud that my State has historically set their reimbursement rate at the Federal recommended level.

Next month, for the first time ever, New York will join 47 other States and drop below this level. And the new requirements will likely cause States to further slash rates. It is not fair to require childcare providers and their employees to bear the cost of new unfunded mandates.

The median income of childcare providers is $19,512, or just over $9.38 per hour. This is less than the Federal poverty level for a family of four, which means many childcare workers themselves are eligible for a subsidy.

I want to be very clear that I and my union strongly support efforts to improve health and safety within childcare. Achieving higher quality requires significant resources. Every day, my union works with members in public office in local, State, and Federal Government to secure economic stability and growth for working families and communities.

Access to affordable childcare is an essential component of this formula. I urge the subcommittee to invest an additional $807,000,000 in CCDBG because stable, high-quality childcare enables parents to work and children to learn and grow.

Thank you.

[The information follows:]

Testimony of Pam Wells,
Owner of Wells Wonder World and

President of Local 100A CSEA

for the Public and Outside Witness Hearing

before the

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

Committee on Appropriations

U.S. House of Representatives

March 25, 2014

Chairman Kingston, Vice-Chairman Womack, and Representative DeLauro – thank you for the opportunity to testify before you today.

My name is Pam Wells. I am the owner of Wells Wonder World, a licensed Group Family Child Care home in Hudson Falls, New York – about an hour north of Albany. I employ members of the community as teaching assistants in my program, some of whom have moved on to open their own family child care programs. I am also the President of CSEA/VOICE Local 100A, which represents organized, independent child care providers, including 20,000 outside of New York City. Since 2007, VOICE has partnered with New York's Office of Children and Family Services (OCFS) in addition to local governments in 57 counties to sustain and improve the child care system that serves New York's working families and children. My colleagues and I work out of our homes to provide high quality, early learning and care for infants, toddlers and young children, ranging from birth through age 12.

Every day my child care colleagues and I see how invaluable child care assistance, through the Child Care and Development Block Grant, CCDBG, is to families struggling to make ends meet. Without CCDBG assistance, many parents would not be able to afford child care at all and could not go to work.

I am here today to respectfully urge you to increase CCDBG funding by $807 million above its current levels to fund the upcoming fiscal year, FY 2015. A substantial increase is essential for following three key reasons:

1) To maintain the numbers of children cared for with federal child care assistance. Without substantial increases, 74,000 children could lose child care assistance.

2) To improve the quality of child care and prepare for new requirements included in expected CCDBG regulations or new law. The CCDBG reauthorization bill, S. 1086, recently passed the Senate with near unanimous support.

3) To improve child care provider payment rates. Improving quality requires good teachers with sound training, and unless we can pay child care providers adequate wages, there is little incentive for them to join or stay with this important field.

I began working as a child care provider 17 years ago in 1997, when I became a licensed Group Family Child Care Provider. I was a single working mother with three young boys and could not find or afford the high-quality child care that I wanted for my sons. Raised in a large

family, I had always enjoyed working with children, and I wanted to operate my own child care program, make it affordable, and provide high-quality care.

I enjoy my work and the satisfaction that comes from nurturing young children and supporting working families in my community. However, some of the hardest things I've had to do are to stop providing care to a family that can no longer afford it or turn away parents whose income is just slightly above the eligibility levels set by the state. Many of the children I have cared for receive child care assistance through CCDBG. Yet, not all children who are eligible for assistance through this program receive it. Why? Because there is not enough funding. Currently, only one in six eligible children receives a subsidy.

It is essential to maintain the numbers of children served

Unfortunately, fewer and fewer eligible children are served by federal child care assistance. Nationwide, 263,000 fewer children received assistance in 2012 than in 2006. According to a recent Center for Law and Social Policy (CLASP) study, total combined child care spending fell from $12.9 billion in 2011 to $11.4 billion in 2012, the most recent year for which data are available. This was the lowest level of spending since 2002. In FY 2012, New York was not able to help 8,100 children from the prior year after losing $325 million in federal child care assistance even though my state put in more money than the required maintenance of effort (MOE) to fill the gap. We need to do better in order to serve the children of New York and our nation.

Increased funding is essential to improve quality and prepare for new requirements

We believe that draft CCDBG regulations proposed by the Department of Health and Human Services' Office of Child Care (OCC) and S. 1086 make important changes. We are concerned, though, that without significant increases in CCDBG funding, New York and other states could be forced to redirect funds that currently provide subsidies for poor children to fulfill the requirements of the new regulations or new law. Without sufficient additional funding, states might further limit the number of families able to access child care subsidies. Many families will likely have to turn to lower-quality care because it is all they can afford. Sacrificing access to affordable child care will not help our shared goal of improving quality in child care. Ultimately, the goal should be to help all eligible families.

Provider Payment Rates

Reimbursing child care providers at reasonable rates is essential to cultivating and sustaining a system of high-quality child care programs. I am proud that my state for many years has set their reimbursement rates at the federally recommended level of the 75th percentile. However, it is getting harder for states to support this commitment. Last year, New York was only one of three states to do so. Next month, New York is set to drop their rates to the 69th percentile, dipping below the recommended level for the first time ever. I worry that the added costs from implementing new regulations or law will further challenge states' capacities to maintain the current numbers of families served, and may further lower reimbursement rates to support the cost of higher-quality care. It is not fair to require child care providers and their employees, a low wage workforce still struggling to recover from the recession, with the unaffordable costs of complying with new requirements, including new training mandates. The median income of child care providers is $19,512, or just over $9.38 per hour. This is less than

the federal poverty level for a family of four, which means many child care workers themselves are eligible for subsidies.

Conclusion

I want to be very clear that I, and my union, strongly support efforts to improve health and safety within child care. Achieving higher quality requires sufficient resources. Every day, my union works with our members and public officials in local, state and federal government to secure economic stability and growth for working families and communities. Access to affordable child care is an essential component of this formula. I urge the Subcommittee to invest an additional $807 million in CCDBG because stable, high-quality child care enables parents to work and children to learn and grow.

Mr. KINGSTON. Thank you, Ms. Wells.

What would be an example of the new training mandate?

Ms. WELLS. Pardon me.

Mr. KINGSTON. What is an example of the new training mandate?

Ms. WELLS. I am sorry. I cannot give you that exact mandate at this time, but I would be more than happy to get that for you.

Mr. KINGSTON. Yes, if you could. Just because what you had said with the unaffordable cost of complying with new mandates, including new training mandates. And I was just wondering if there was some specific mandates that were not necessary, duplicative of something that was already out there.

And so if you do have an example, that would be helpful.

Ms. WELLS. I would be more than happy to provide that for you.

Mr. KINGSTON. Okay. Thanks.

Rosa.

Ms. DELAURO. I just want to applaud your efforts. In many conversations with women all over the country and with families, actually—it is not just about women—and with the empirical data that is so rich, one of the single biggest issues that women and their families are dealing with and causes one of the biggest areas of economic insecurity for families today is the cost of childcare and the availability of childcare.

And the two are linked, accessibility and affordability. And I think it is something I would applaud the President, who has talked about early childhood education, preschool. But we have to deal with partnerships at the Federal level, at State level, with agencies in order to be able to provide that kind of safe, affordable, and accessible childcare.

My colleague in the Senate, Chris Murphy, and I have looked at the way in which we could increase and double the childcare tax credit for families from $5,000 to $10,000 to make it more affordable. We have to deal with child tax credits, the refundability of child tax credits.

For families, oftentimes childcare can cost as much as a mortgage per month, and it is one of the leading issues that is on the minds of families, and it is one of the serious causes of economic insecurity among women in this country. And it is part of an economic agenda that my colleagues and I have put together that addresses pay equity and rising pay, work-family balance in terms of paid leave and paid family and medical leave, and addresses the issue of childcare.

So, and we want to make sure that childcare workers are paid what they—for the job that they are doing. We place enormous responsibility on our childcare workers. They take care of the most precious things in our lives, and that is our babies. These are our children.

And they are significantly underpaid when you take a look at those scales. So, again, many thanks to you for what you are doing. Appreciate it.

Ms. WELLS. Thank you.

Mr. KINGSTON. And let me ask you, invite you to profile one of your clients. Maybe a single mom with an income level and what she would need to pay you. Just for the record, it might be interesting, somebody who comes to you.

Ms. WELLS. Thank you very much.
Mr. KINGSTON. Okay. Thank you.

Written Testimony by

Kenneth A. Buckwalter, MS, MD, FACR, SSR President

on behalf of the

Society of Skeletal Radiology

on FY 2015 Appropriations for the National Institutes of Health

Submitted March 28, 2014, for the Record to the

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

Committee on Appropriations

United States House of Representatives

The **Society of Skeletal Radiology** recommends a funding level of **$32.0 billion for NIH** and **$397 million for the NIBIB** in fiscal year (FY) 2015

Thank you for providing the **Society of Skeletal Radiology** with the opportunity to submit written testimony on fiscal year 2015 funding for the National Institutes of Health (NIH).

The **Society of Skeletal Radiology (SSR)** is dedicated to the goal of encouraging and supporting the development of expertise in the subspecialty of musculoskeletal radiology. There are more than 1,000 society members from nearly every state in the U.S. Many of our members are from academic radiology departments and perform imaging research critical for the diagnosis and staging of disease.

Looking back to fiscal year 2004, NIH funding stood at $27.8 billion in nominal dollars. A decade later, NIH now stands at $30.0 billion – meaning that our engine for medical

breakthroughs in the U.S. has grown a total of just over 5% over the past eleven years, or at an annualized rate of 0.5%. While we acknowledge that the Subcommittee is not responsible for the larger budget constraints, the annualized growth rate for NIH over the past decade continues to not reflect that of an economy whose future depends on innovation, technological breakthrough, and lower healthcare costs made possible by research discoveries.

NIH Director Francis Collins, M.D., Ph.D. stated before the Subcommittee on March 5, 2013 that other nations are "ramping up their support of biomedical research because they've read our playbook." Indeed, unlike the U.S., both emerging and developed economies continue to prioritize public funding for medical research and development. China alone is committing an average of $60 billion per year to biotechnology over the next five years – double the budget of the NIH. If NIH had continued its historical annual rate of growth (6.5%) from the 1960s to 1998 after the "doubling," it would now be supported at $46.7 billion a year. Even a smaller but sustainable level of 4% annual growth since 2004 would put NIH funding at $38.5 billion today.

It is time to move NIH back into meaningful positive direction, ensuring that it can sustain and grow the number of multi-year investigator-initiated research grants, the foundation of our nation's biomedical research enterprise. We ask that the Subcommittee prioritize NIH even within the statutorily imposed budget caps, and begin reinvigorating medical research with an appropriation of $32.0 billion in Fiscal Year 2015.

The National Institute of Biomedical Imaging and Bioengineering as an Incubator and Supplier of New Technologies

Since the 1980s, many clinical and technological advances in CT, MRI, PET imaging, and image-guided therapies have been developed through funding from the National Institute for Biomedical Imaging and Bioengineering (NIBIB). Radiology research is truly an interdisciplinary science, bringing together physicians, physicists, mathematicians, chemists, computer scientists, physiologists and others from numerous scientific fields. This strong and diverse research pipeline has helped solidify the U.S as the world leader in the basic research, development, and commercialization of advanced medical imaging technologies. It also makes the investment in NIBIB's research particularly valuable, as there are three distinct outputs from NIBIB research:

1) ***bench-to-bedside imaging tools*** that help medical professionals diagnose, treat, and monitor a wide array of diseases and conditions, saving millions of lives each year;
2) ***bench-to-bench interdisciplinary research tools*** that have given thousands of researchers in other fields game-changing new ways to tackle the diseases that they study; and
3) ***a pipeline for commercial imaging products,*** as medical imaging devices represent one of the nation's healthiest export industries, providing tens of thousands of high-skilled jobs across the country and adding positively to the nation's gross domestic product.

Despite its small stature ($327 million in FY 2014), the NIBIB is especially important as the federal incubator for innovation in the rapidly moving field of medical imaging. Given its three-legged return on investment as a supplier of new technologies for patient care, a developer of game-changing new technologies for scientists in all fields, and a pipeline for a key domestic sector, we request a shift in the NIH portfolio for greater investment in imaging R&D.

A global benchmark for R&D spending for an innovation economy is 3% of GDP. We recommend that the NIH portfolio begin to be readjusted in FY2015 to allow for this same investment in biotechnology, bioengineering and biomedical imaging R&D, increasing the proportion of funding to NIBIB from the current 1.10% of the NIH budget to 3.0% over the next five years. This budget path and reallocation across NIH would call for a $70 million increase for NIBIB in FY2015, setting the budget for NIBIB at $397 million.

Written Testimony by Scott C. Goodwin, MD, FSIR, President, on behalf of the Society of Interventional Radiology and John A. Kaufman, MD, MS, FSIR, Chair, on behalf of the Society of Interventional Radiology Foundation on

FY 2015 Appropriations for the National Institutes of Health

Submitted March 28, 2014, for the Record to the

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

Committee on Appropriations

United States House of Representatives

The Society of Interventional Radiology recommends a funding level of $32.0 billion for NIH and $397 million for the NIBIB in fiscal year (FY) 2015

Thank you for providing the Society of Interventional Radiology with the opportunity to submit written testimony on fiscal year 2015 funding for the National Institutes of Health (NIH). The Society of Interventional Radiology (SIR) is a professional medical association that represents 5,000 members who are practicing in the specialty of vascular and interventional radiology. The Society is dedicated to improving public health through pioneering advances in minimally-invasive, image-guided therapy. Our members are at the forefront of new and minimally invasive therapies to treat an array of diseases and conditions without surgery. Interventional radiology treatments have become first-line care for a wide variety of conditions and patients, including peripheral arterial disease, deep vein thrombosis, uterine fibroids, cancer, and stroke patients.

SIR Foundation is a scientific foundation dedicated to fostering research in interventional radiology for the purposes of advancing scientific knowledge, increasing the number of skilled investigators, and developing innovative therapies that lead to improved patient care and quality of life. The Foundation is committed to fostering the development and enhancement of innovative, minimally invasive, image-guided therapies from inception to mature clinical application and to conduct educational programs in the service of its mission.

Looking back to fiscal year 2004, NIH funding stood at $27.8 billion in nominal dollars. A decade later, NIH now stands at $30.0 billion – meaning that our engine for medical breakthroughs in the U.S. has grown a total of just over 5% over the past eleven years, or at an annualized rate of 0.5%. While we acknowledge that the Subcommittee is not responsible for the larger budget constraints, the annualized growth rate for NIH over the past decade continues to not reflect that of an economy whose future depends on innovation, technological breakthrough, and lower healthcare costs made possible by research discoveries.

NIH Director Francis Collins, M.D., Ph.D. stated before the Subcommittee on March 5, 2013 that other nations are "ramping up their support of biomedical research because they've read our playbook." Indeed, unlike the U.S., both emerging and developed economies continue to prioritize public funding for medical research and development. China alone is committing an average of $60 billion per year to biotechnology over the next five years – double the budget of the NIH. If NIH had continued its historical annual rate of growth (6.5%) from the 1960s to 1998 after the "doubling," it would now be supported at $46.7 billion a year. Even a smaller but sustainable level of 4% annual growth since 2004 would put NIH funding at $38.5 billion today.

It is time to move NIH back into meaningful positive direction, ensuring that it can sustain and grow the number of multi-year investigator-initiated research grants, the foundation of our nation's biomedical research enterprise. We ask that the Subcommittee prioritize NIH even within the statutorily imposed budget caps, and begin reinvigorating medical research with an appropriation of $32.0 billion in Fiscal Year 2015.

The National Institute of Biomedical Imaging and Bioengineering as an Incubator and Supplier of New Technologies

Since the 1980s, many clinical and technological advances in CT, MRI, PET imaging, and image-guided therapies have been developed through funding from the National Institute for Biomedical Imaging and Bioengineering (NIBIB). Radiology research is truly an interdisciplinary science, bringing together physicians, physicists, mathematicians, chemists, computer scientists, physiologists and others from numerous scientific fields. This strong and diverse research pipeline has helped solidify the U.S as the world leader in the basic research, development, and commercialization of advanced medical imaging technologies. It also makes the investment in NIBIB's research particularly valuable, as there are three distinct outputs from NIBIB research:

1) ***bench-to-bedside imaging tools*** that help medical professionals diagnose, treat, and monitor a wide array of diseases and conditions, saving millions of lives each year;

2) ***bench-to-bench interdisciplinary research tools*** that have given thousands of researchers in other fields game-changing new ways to tackle the diseases that they study; and
3) ***a pipeline for commercial imaging products,*** as medical imaging devices represent one of the nation's healthiest export industries, providing tens of thousands of high-skilled jobs across the country and adding positively to the nation's gross domestic product.

Despite its small stature ($327 million in FY 2014), the NIBIB is especially important as the federal incubator for innovation in the rapidly moving field of medical imaging. Given its three-legged return on investment as a supplier of new technologies for patient care, a developer of game-changing new technologies for scientists in all fields, and a pipeline for a key domestic sector, we request a shift in the NIH portfolio for greater investment in imaging R&D.

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Written Testimony by Richard Barth, MD on behalf of the Society for Pediatric Radiology

on

FY 2015 Appropriations for the National Institutes of Health

Submitted March 28, 2014, for the Record to the

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

Committee on Appropriations

United States House of Representatives

The Society for Pediatric Radiology recommends a funding level of **$32.0 billion for NIH** and **$397 million for the NIBIB** in fiscal year (FY) 2015

Thank you for providing the **Society for Pediatric Radiology** with the opportunity to submit written testimony on fiscal year 2015 funding for the National Institutes of Health (NIH). SPR formed in 1958, was the first subspecialty society in radiology, now with over 2000 members, whose practice focuses on accurate diagnosis and improving the treatment of children via imaging. SPR's members have led research and educational efforts since 2001 to raise awareness in both the public and the medical community on the importance of minimizing radiation dose in the imaging of children. We are proud to have called for the formation in 2007 of the Alliance for Radiation Safety in Pediatric Imaging, now with over 80 organizations world-wide committed to the same goal. SPR represents radiologists in every specialty as our organizing principle is the pediatric patient.

Looking back to fiscal year 2004, NIH funding stood at $27.8 billion in nominal dollars. A decade later, NIH now stands at $30.0 billion – meaning that our engine for medical

breakthroughs in the U.S. has grown a total of just over 5% over the past eleven years, or at an annualized rate of 0.5%. While we acknowledge that the Subcommittee is not responsible for the larger budget constraints, the annualized growth rate for NIH over the past decade continues to not reflect that of an economy whose future depends on innovation, technological breakthrough, and lower healthcare costs made possible by research discoveries.

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JOHN D. ROSENBERG

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March 20, 2014

My cousin is fifty seven years old and has a diagnosis of severe or profound mental retardation. Since 1974, she has lived on a bucolic campus owned by the State of Texas in Denton. Because she is with other people with similar diagnosis and the area she lives is protected by some acreage, she is able to walk freely to different places to participate in various activities. She also enjoys programs that take her, under supervision, to urban settings. She does not live in an "institution," she lives in an environment that is the least restrictive for her and people like her.

If forced to move the "the community," my cousin would not be able to leave her facility to go outside without expensive, labor intensive supervision. Her freedom of movement and life would be severely restricted. That environment would be dangerous for her.

My cousin and others similarly situated should have the freedom to choose to live in an environment that best suits their needs, like most people in this country.

A partial list of offending federal programs included in the DHHS appropriations that are trying to restrict my cousin and those people similarly situated are National Council on Disability (NCD), Administration on Intellectual and Developmental Disabilities (AIDD), DD Act programs (state councils on developmental disabilities, P&A programs).

Please continue to provide federal money and support for state-run programs that allow my cousin's guardian and her family make their own decision about the best place to live.

John Rosenberg

C · H · I
CALIFORNIA HEALTHCARE INSTITUTE

Statement of Todd E. Gillenwater, President & CEO
California Healthcare Institute (CHI)

Submitted to the House Appropriations Committee
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

Budget Hearing on the Future of Biomedical Research
March 26, 2014

CHI - California Healthcare Institute, the statewide public policy organization representing California's leading biomedical innovators – over 275 research universities and private, nonprofit institutes, venture capital firms, and medical device, diagnostic, biotechnology and pharmaceutical companies – appreciates the opportunity to present its views on the critical need for Congress to support increased and sustained funding for the National Institutes of Health (NIH) as part of this important hearing on the future of biomedical research.

Groundbreaking technologies create a multiplier effect, sometimes giving rise to entire new industries. In the 1970s, few could have predicted the far-reaching impact recombinant DNA (rDNA) would have on the world. Yet this science, developed by researchers at UC San Francisco and Stanford and funded by the NIH, has improved agriculture, vaccines, drug development, genetic screening and many other areas. Beyond its contributions to human health, rDNA has generated high-income jobs – today, California's more than 2,300 biomedical companies and institutions, clustered throughout the state, lead the world in life sciences research and development, which has led to groundbreaking therapies and technologies to diagnose, treat and prevent conditions such as cancer, cardiovascular disease, diabetes, HIV/AIDS, chronic pain, Alzheimer's, Parkinson's Disease, and others. Just as important, the sector is an increasingly important component of our state's economic engine, employing nearly 270,000 people, paying

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$15.5 billion in wages and accounting for $20 billion in exports. None of this would be possible without the important basic, clinical and translational science investments made by NIH.

In 2013, California academics are expected to receive NIH grants exceeding $3 billion, far and away leading the nation. Institutions like UC San Francisco, UC San Diego, Stanford and UCLA lead the way, each topping $300 million in grant revenue. In recent years, though, government support for basic research has become increasingly constrained. NIH funding, which has been stagnant for more than a decade, has taken a further hit from sequestration, which has cut research grants by 5 percent. While it's good news that California is getting a larger percentage of this grant revenue, the total pie is getting smaller.

The President's budget requests $30.4 billion for NIH in fiscal year 2015, representing a slight $211 million increase over FY14 actual levels. Although only 0.7% higher than last year, this proposed increase will support an estimated 9,326 new and competing grants, approximately 329 more than in FY14. CHI acknowledges and appreciates that this slight increase for NIH was prioritized within a larger Department of Health and Human Services budget that is decreased from the previous fiscal year. Especially given our austere fiscal climate, the president should be applauded for this commitment to science.

However, spending cuts and sequestration have significantly reduced NIH's budget, to the tune of approximately $1.6 billion in fiscal year 2013 alone. Quite simply, the administration's budget request for FY15 unfortunately falls far short of reversing the damage done by a decade of flat funding and recent cuts from sequestration.

NIH-funded research serves as the foundation for scientific advancements that offer hope to millions. This fact was recognized and encouraged through a five-years-long initiative to double the NIH budget between 1998-2003. Since then, however, chronic underfunding of the agency at levels below the rate of medical inflation, compounded by mandatory cuts imposed by sequestration in previous fiscal years, have put America at risk of ceding our global leadership in biomedical research and innovation.

CHI was pleased to endorse H.R. 2019, the *Gabriella Miller Kids First Research Act*, recently passed by both the House and Senate. If signed into law by the President, this important legislation will reallocate scarce public resources to support pediatric research sponsored by NIH, and help make clear that the health and well-being of our children is a national priority. But we must do more.

To that end, CHI is enthusiastic about and supportive of an ongoing bipartisan Congressional effort to elevate NIH funding to at least $32 billion in FY15, which will help NIH make important progress in recovering from the immeasurable losses caused by declining research budgets over the past decade. As we look to the future, we are committed to working with Congress and other stakeholders to reinvigorate biomedical research funding through a long-term strategic effort to grow NIH base funding to levels that will again put the U.S. on a path toward not just sustaining but truly leading biomedical research and innovation for the 21st Century.

We would be pleased to provide additional information on the important role NIH funding has in fueling biomedical and life sciences innovation, promoting venture investment, and creating and retaining jobs in our state. Thank you again for the opportunity to present our views.

Testimony of the American Nurses Association Regarding
Fiscal Year 2015 Appropriations for the Title VIII Nursing Workforce Development Programs and Nurse-Managed Health Clinics

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

March 19, 2014

Submitted by:
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The American Nurses Association (ANA) appreciates the opportunity to comment on Fiscal Year (FY) 2015 appropriations for the Title VIII Nursing Workforce Development Programs and Nurse-Managed Health Clinics. Founded in 1896, ANA is the only full-service professional association representing the interests of the nation's 3.2 million registered nurses (RNs) and advanced practice registered nurses (APRNs-including certified nurse-midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists) through its state nurses associations, and organizational affiliates. The ANA advances the nursing profession by fostering high standards of nursing practice, promoting the rights of nurses in the workplace, and projecting a positive and realistic view of nursing.

As the largest single group of clinical health care professionals within the health system, licensed registered nurses are educated and practice within a holistic framework that views the individual, family and community as an interconnected system that can keep us well and help us heal. As the nation works towards restructuring the healthcare system by focusing on expanding access, decreasing cost, and improving quality; a significant investment must be made in strengthening the nursing workforce.

We are grateful to the Subcommittee for your past commitment to Title VIII funding, and we understand

the immense fiscal pressures the Subcommittee is facing. However, ANA respectfully requests you support **$251 million for the Nursing Workforce Development programs** authorized under Title VIII of the Public Health Service Act in FY 2015. Additionally, we respectfully request **$20 million for the Nurse-Managed Health Clinics** authorized under Title III of the Public Health Service Act in FY 2015. While we recognize the reality of the current fiscal environment, we also firmly believe this request is necessary given the demand for nursing services is steadily on the rise.

Demand for Nurses Continues to Grow

A sufficient supply of nurses is critical in providing our nation's population with quality health care now and into the future. Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs) are the backbone of hospitals, community clinics, school health programs, home health and long-term care programs, and serve patients in many other roles and settings. The Bureau of Labor Statistics' (BLS) *Employment Projections for 2012-2022*, indicates the expected number of practicing nurses will grow from 2.862 million in 2012 to 3.437 million in 2022, an increase of 574,400, or 20.1%. In addition, nurse practitioners are one of the fastest growing occupations according to the BLS projections, noting there will be a 33.7% increase between 2012-2022.

Contrary to the good news that there are a growing number of nurses, the current nurse workforce is aging. According to the *2008 National Sample Survey of Registered Nurses*, over one million of the nation's 2.6 million practicing RNs are over the age of 50. Within this population, more than 275,000 nurses are over the age of 60. As the economy continues to rebound, many of these nurses will seek retirement, leaving behind a significant deficit in the number of experienced nurses in the workforce. BLS has projected that 555,100 RNs and APRNs will retire or otherwise leave the labor force by 2022—a tsunami of RN retirements. In fact, with RN retirements in the mix, the nation will need to have produced 1.13 million new RNs by 2022 to fill those jobs. A shortage of this magnitude would be twice as large as any shortage experienced by this country since the 1960s. Cuts to Title VIII funding would be

detrimental to the health care system and the patients we serve.

Furthermore, as of January 1, 2011 Baby Boomers began turning 65 at the rate of 10,000 a day. It is estimated that over 80 million Baby Boomers reached age 65 last year. With this aging population, the healthcare workforce will need to grow as there is an increase in demand for nursing care in traditional acute care settings as well as the expansion of non-hospital settings such as home care and long-term care.

Title VIII: Nursing Workforce Development Programs

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.), include programs such as **Nursing Loan Repayment Program and Scholarships Program,** (Sec. 846, Title VIII, PHSA); **Advanced Nursing Education (ANE) Grants;** (Sec. 811), **Advanced Education Nursing Traineeships, (AENT); Nurse Anesthetist Traineeships (NAT): Comprehensive Geriatric Education Grants,** (Sec. 855, Title VIII, PHSA); **Nurse Faculty Loan Program,** (Sec. 846 A, Title VIII, PHSA); and **Nursing Workforce Diversity Grants,** (Sec. 821). These programs support the supply and distribution of qualified nurses to meet our nation's healthcare needs.

Without support for Title VIII funding and nursing education; there will be a shortage of nurse educators. With a shortage of nurse educators, schools will have to turn away nursing students. With less financial assistance to deserving nursing students; there will be fewer nursing students. With fewer nursing students, there will be fewer nurses. As noted above, the nursing shortage will have 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 March 17, 2011 issue of the *New England Journal of Medicine* shows that inadequate staffing is tied to higher patient mortality rates. The study supports findings of previous studies and finds that higher than typical rates of patient admissions, discharges, and transfers during a shift were associated with increased mortality – an indication of the

important time and attention needed by RNs to ensure effective coordination of care for patients at critical transition periods.

Over the last 50 years, Title VIII programs have provided the largest source of federal funding for nursing education; offering financial support for nursing education programs, individual students, and nurse educators. These programs bolster nursing education at all levels, from entry-level preparation through graduate study and in many areas including rural and medically underserved communities.

The American Association of Colleges of Nursing's (AACN) *Title VIII Student Recipient Survey* gathers information about Title VIII dollars and its impact on nursing students. The 2012-2013 survey, which included responses from over 800 students, stated that the Title VIII programs played a critical role in funding their nursing education. The survey showed that 78% 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. Between FY 2005 and 2012 alone, the Title VIII programs supported over 450,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities.

The Title VIII programs also address the need for more nurse faculty. Data from AACN's 2013-2014 enrollment and graduations survey show that nursing schools were forced to turn away 78,089 qualified applications from entry-level baccalaureate and graduate nursing programs in 2013, and faculty vacancy was a primary reason. There are also replacement and expansion need in nursing colleges. The total instructors needed by 2022 will be 91,800. In order to meet that need the nursing colleges will have to hire 34,200 more instructors. The Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education provided they serve as faculty for four years after graduation.

Monies you appropriate for these programs help move nurses into the workforce without delay. Your investment in programs, and the nurses that participate, is returned by more students entering into the profession and serving in rural and underserved areas; by nurses continuing with their education and

studying to be nurse practitioners, thereby addressing our nation's growing need for primary care providers; or by going on to become a nurse faculty member and teaching the next generation of nurses. 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. Registered Nurses (RNs) and Advanced Practice Nurses (APRNs) are key providers whose care is linked directly to the availability, cost, and quality of healthcare services. For these reasons and many more, we again respectfully request you appropriate **$251 million for the Nursing Workforce Development programs** authorized under Title VIII of the Public Health Service Act in FY 2015.

Nurse-Managed Health Clinics

A health care system must value primary care and prevention to achieve an improved health status of individuals, families and the community. Nurses are strong supporters of community and home-based models of care. We believe that the foundation for a wellness-based health care system is built in these settings and reduces the amount of both financial expenditures and human suffering. ANA supports the renewed focus on new and existing community-based programs such as Nurse Managed Health Centers (NMHCs).

Currently, there are more than 200 Nurse Managed Health Centers (NMHCs) in the United States which have provided care to over 2 million patients annually. ANA believes that Nurse Managed Health Centers (NMHCs) are an efficient, cost-effective way to deliver primary health eare services. NMHCs are effective in disease prevention and early detection, management of chronic conditions, treatment of acute illnesses, health promotion, and more. These clinics are also used as clinical sites for nursing education.

We respectfully request the committee provide $20 million for the Nurse-Managed Health Clinics authorized under Title VIII of the Public Health Service Act in FY 2015.

Thank you for your time and your attention to this matter.

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American College of Radiology (ACR)

Testimony to the House LHHS Appropriations Subcommittee

In Support of Increased Funding in FY 2015 for the National Institutes of Health,

National Cancer Institute, and

National Institute of Biomedical Imaging and Bioengineering

Submitted March 21, 2014

The American College of Radiology (ACR)—a professional organization serving more than 35,000 radiologists, radiation oncologists, interventional radiologists, nuclear medicine physicians, and medical physicists—recommends increased funding for the National Institutes of Health (NIH) in fiscal year (FY) 2015 appropriations legislation. Specifically, the ACR endorses the position of the Ad Hoc Group for Medical Research—a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry—that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in our nation's investment in medical research. That recommended funding level is approximately $1.874 billion above the President's Budget request for FY 2015. Additionally, the ACR joins the Ad Hoc Group in urging Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable

scientific opportunities, discourage young scientists, jeopardize our economic future, and threaten medical progress and continued improvements in our nation's health.

The value of the NIH to American taxpayers is immeasurable, and there have been several recent examples of impactful science in the biomedical imaging domain that would not have been realized and translated swiftly into patient care without NIH support and involvement. For instance, the NIH National Cancer Institute's (NCI) nearly decade-long National Lung Screening Trial—conducted by the American College of Radiology Imaging Network (ACRIN) and Lung Screening Study group—found that computed tomography (CT) screening of high risk patients could reduce deaths from lung cancer by 20 percent versus chest X-ray screening. Another NCI-supported success, the National CT Colonography Trial—also conducted by ACRIN—found that virtual colonoscopy was effective as a screening method for colorectal cancer thanks to its accuracy, safety, cost-effectiveness, and patient acceptability compared to more invasive and potentially intimidating screening options. The Radiation Therapy Oncology Group (RTOG) now a member of the NRG Oncology Group in the new National Clinical Trials Network (NCTN), is the international leader in investigating the appropriateness of advanced technologies such as proton therapy and intensity modulated radiation therapy (IMRT) in multi-center randomized trials examining the safety, effectiveness, and quality of life implications of these treatments. Additional ACRIN (now ECOG-ACRIN in the NCTN) and NRG activities under NCI's purview promise to advance the areas of personalized early cancer detection, identify biomarkers to predict treatment effectiveness, reduce the rate of false-positive imaging examinations, and improve cancer screening outcomes. However, NCI's funding of

cooperative groups in the evolved National Clinical Trials Network (NCTN) has been severely cut and the groups' planned budgets are considerably below expectations. We urge Congress to restore the full funding approved by the NCI's Board of Scientific Advisors for the organizations that transitioned from the cooperative group program into the new NCTN.

Although smaller than NCI, the NIH National Institute of Biomedical Imaging and Bioengineering (NIBIB) has likewise been successful in advancing the science behind evolving biomedical imaging technologies and techniques. The ACR played a key role in NIBIB's creation through co-founding a coalition of likeminded organizations and working with federal policymakers to successfully advance the establishing legislation in 2000. Since its inception, NIBIB has been particularly effective in supporting training initiatives, educational symposia, and international collaborations, as well as fostering future generations of biomedical imaging and bioengineering scientists via innovative initiatives and communications.

Without significantly increased funding levels for NIH in FY 2015 and beyond, America's leadership in biomedical research will decline, scientists will be increasingly discouraged by the lack of funding opportunities, and innovative technologies and techniques (such as those supported through NCI and NIBIB) will not be appropriately researched and translated into patient care. Therefore, the ACR endorses the Ad Hoc Group for Medical Research's recommendation that NIH receive at least $32 billion in FY 2015 as part of a

multi-year increase, and that Congress and the Administration work together to decisively end sequestration.

Thank you for your consideration. Please contact Gloria R. Romanelli, JD, Senior Director of Legislative and Regulatory Relations (gromanelli@acr.org), or Michael Peters, Director of Legislative and Regulatory Affairs (mpeters@acr.org), at (202) 223-1670 if you have any questions or would like additional information about the important contributions of NCI and NIBIB.

Statement of Patricia Harrison
President and CEO, Corporation for Public Broadcasting
Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, U.S. House Committee on Appropriations
March 21, 2014

Chairman Kingston and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service—public television and public radio—on-air, online and in the community. The Corporation for Public Broadcasting (CPB) requests level funding of $445 million for Fiscal Year 2017 and $27.3 million for the Department of Education's Ready To Learn program in Fiscal Year 2015.

Forty-six years after passage of the Public Broadcasting Act, this uniquely American public-private partnership is keeping its promise to the American people by providing a safe place where children can learn on-air and online; providing high-quality educational content for teachers in the classroom and children schooled at home; providing reliable and trusted news and information; and providing emergency alert services. Either by looking at each station individually or public media as a whole, this public-private partnership is making a big difference in the lives of individuals and communities.

Today we are a system that comprises more than 1,400 locally owned and locally operated public radio and television stations serving rural and urban communities throughout the country. More than 98% of the American people turn to American public media for high quality content that educates, informs, inspires and entertains. Public media's commitment to early and lifelong learning, available to all citizens, helps strengthen our civil society and our democracy. Our trusted, noncommercial services available for free to all Americans is especially important to those living in rural communities where the local public media station is sometimes the only source of broadcast news, information and educational programming.

I understand that this committee is faced with the challenging task of allocating scarce federal resources to a number of organizations, all doing worthy and important work. The financial support for the public broadcasting system that is derived from the federal appropriation is the essential investment keeping public media free and commercial free for all Americans. Former President Ronald Reagan said, "government should provide the spark and the private sector should do the rest." And what stations do, with the spark of federal dollars that amounts to approximately 10 to 15 percent of a stations' budget, results in a uniquely entrepreneurial and American public media system with a track record of proven benefits delivered through stations to the American people.

The federal investment through CPB is the foundation on which the entire system is built. These critical funds leverage vital investments from other sources. Undermining this foundation would put the entire structure in jeopardy. While private donations and existing funding sources can help defray considerable costs for the much-honored programs of public television and radio—nonfederal funding represents five of every six dollars invested annually in public broadcasting—the federal investment is indispensable to sustaining the operations of public broadcasting stations, the public service mission they pursue, local community-based accountability, and the universal service to which the Public Broadcasting Act aspires.

Further, it is this initial investment in public media that keeps it commercial free and available to all Americans for free. However, smaller stations serving rural, minority and other underserved communities are hard pressed to raise six times the federal appropriation, which can represent as much as 40 percent of their budget.

Public media's contribution to education—from early childhood through adult learning—is well documented. We are America's largest classroom, with proven content available to all

children, including those who cannot afford preschool. Our content is repeatedly regarded as "most trusted" by parents, caregivers and teachers.

CPB's work with the Department of Education's Ready To Learn program is an excellent example of how public media brings together high-quality educational content with on-the-ground work in local communities. We also invest in research that demonstrates and promotes the effectiveness of this content in formal and informal educational settings.

We talk a lot about content that matters and engagement that counts, further defining public media from commercial media. An example of this is CPB's "American Graduate: Let's Make it Happen" Initiative, which tells the story behind the statistic of one million American young people failing to graduate every year from high school. Our stations told the stories and communities throughout the country responded. More than 75 public media stations located in 33 states with at-risk communities are working with more than 1000 national and community-based partners to bring together diverse stakeholders and community organizations; filling gaps in information, resources and solutions; sharing best practices for teacher training and student engagement; creating local programming around the dropout issue unique to their communities, and leveraging digital media and technology to engage students in an effort to keep them on the path to graduation. Those numbers are now declining because what our stations do, counts. But American Graduate is just one example of how public media stations are using their spectrum for the public good.

Building on our education commitment, CPB recently announced that it will expand on these successful models to bring meaningful impact and change to more communities at risk. Through the recently created $20 million American Graduate/PBS KIDS Fund, CPB and PBS will invest in the development of new tools to help parents better prepare their children ages 2 –

8 for educational success, to support teacher development, and to engage middle and high school youth to improve learning.

Public media is utilizing today's technology to provide content of value to millions of citizens who trust us to deliver content that matters and is relevant to their lives today. CPB strategically focuses investments through the lens of what we refer to as the "Three D's" — Digital, Diversity and Dialogue. This refers to support for innovation on digital platforms, extending public media's reach and service over multiple platforms; content that is for, by and about Americans of all backgrounds; and services that foster dialogue between the American people and the public service media organizations that serve them. CPB funding enables stations to provide content of consequence and to keep faith with the visions of political, educational, philanthropic and community leaders who have seen in public broadcasting the potential to strengthen our nation by promoting lifelong learning and an informed citizenry.

As the steward of these important taxpayer dollars, CPB ensures that 95 cents of every dollar received goes to support local stations and the programs and services they offer to their communities; no more than five cents of every dollar goes to the administration of funding programs and overhead.

The Public Broadcasting Act ensures diversity in this programming by requiring CPB to fund independent and minority producers. CPB fulfills this obligation, in part, by funding the Independent Television Service, the five Minority Consortia entities in television (African American, Latino, Asian American, Native American and Pacific Islander), several public radio consortia (Latino Public Radio Consortia, African American Public Radio Stations, and Native Public Media) and numerous minority public radio stations. In addition, CPB, through its

Diversity and Innovation fund, makes direct investments in the development of diverse primetime and children's broadcast programs as well as innovative digital content.

As newspapers across the country have scaled back their operations, public media has stepped into the void. Local stations have been working to fill the gap with creative ventures and partnerships, such as our seven multimedia local journalism centers (LJCs) that are providing their communities with much-needed local, regional and statewide coverage.

For an investment of approximately $1.35 per American per year, public media stations are able to train teachers and help educate America's children; provide in-depth journalism that informs citizens about issues in their neighborhoods, their country, and around the globe; make the arts accessible to all Americans; and provide emergency alert services for their communities.

CPB's FY 2017 request of $445 million balances the fiscal reality facing our nation with our statutory mandate to provide a valuable and trusted service to all Americans. Today, the challenges we face are more complex than ever and require new levels of thinking, innovation, and collaboration. Community organizations often work in isolation, shouldering the burden of solving societal problems. But public media is the essential link, uniquely poised to add real value. CPB's FY 2017 request will allow stations to enhance their role as a trusted source of information and as a convener, help communities understand issues, and mobilize them toward positive, sustainable outcomes.

Mr. Chairman and members of the subcommittee, this is only part of the story of our public media system in America. Public media is a national treasure that is available and accessible to all Americans. Every day public media works to strengthen and advance our civil society. I thank you for allowing me to submit this testimony and urge you to consider our request for funding.

Association of Rehabilitation Nurses
Written Testimony to the House Labor-Health and Human Services Appropriations Subcommittee
Regarding Fiscal Year 2015 Nursing and Rehabilitation Related Funding
Submitted by: ARN President, Kris Mauk, PhD DNP RN CRRN GCNS-BC GNP-BC, FAAN
March 28, 2014

On behalf of the Association of Rehabilitation Nurses (ARN), I am pleased to submit this statement for the record recommending **$251 million in FY 2015 funding for federal Nursing Workforce Development programs at HRSA; $150 million in FY 2015 funding for NINR; $10 million for the CDC's TBI registries and surveillance, prevention and national public education and awareness efforts; and $12 million for HRSA's Federal TBI State Grant Program and the Protection and Advocacy Systems Grant Program.** ARN represents nearly 12,000 rehabilitation nurses that 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. We 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, which empowers these individuals when they return home, or to work, or school. Rehabilitation nurses often teach 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. We base our practice on rehabilitative and restorative principles by: (1) managing complex medical issues; (2) collaborating with other interprofessional 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, home health, and private practices, just to name a few. 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 for individuals affected by chronic illness and/or physical disability.

According to the Bureau of Labor Statistics' (BLS) *Employment Projections for 2012-2022*, the expected number of practicing nurses will grow from 2.71 million in 2012 to 3.24 million in 2022, an increase of 526,800, or 19.4%. The number of job openings due to demand for registered nursing services and replacements brings the total of additional RNs needed to 1.053 million by 2022. In addition, according to BLS projections, there will be a 33.7% increase in nurse practitioners between 2012-2022, making it one of the fastest growing occupations in the US. The demand for nurses will continue to grow as the baby-boomer population ages, nurses retire, and the need for healthcare

intensifies. Implementation of the new health reform law will also increase the need for a well-trained and highly-skilled nursing workforce.

For nearly 50 years, the Nursing Workforce Development programs, authorized under Title VIII of the *Public Health Service Act*, have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs. 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. Today, the Title VIII programs are essential to ensure the demand for nursing care is met. Between FY 2005 and 2012 alone, the Title VIII programs supported over 450,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities.

ARN strongly supports the national nursing community's request of $251 million in FY 2015 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 ability 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 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 2015 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 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. Through grants, research, training, and interprofessional collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. NINR's broad mandate includes seeking to prevent and delay disease and to ease the symptoms associated with both chronic and acute illnesses.

ARN respectfully requests $150 million in FY 2015 funding for NINR to continue its efforts to address issues related to chronic and acute illnesses.

Traumatic Brian Injury (TBI)

According to the Brain Injury Association of America, 2.4 million people sustain a traumatic brain injury (TBI) each year.[1] This figure does not include the 150,000 cases of TBI suffered by soldiers returning from wars in Afghanistan and conflicts around the world.

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

[1] http://www.biausa.org/living-with-brain-injury.htm

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.

ARN urges Congress to support $10 million for CDC's TBI registries and surveillance programs and $12 million for HRSA's Federal TBI State Grant Program and the Protection and Advocacy Systems Grant Program in FY 2015.

Conclusion

ARN appreciates the opportunity to share our priorities for FY 2015 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 2015 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.

Statement of Kristen Tracy
President, National Association of Foster Grandparent Program Directors (NAFGPD)

Submitted to the House Appropriations Committee
Subcommittee on Labor, Health and Human Services, and Education
March 28, 2014

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit this testimony in support of FY 2015 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, or "Senior 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 (CNCS). I respectfully request that the Subcommittee provide at least $107,702,000 for FGP in FY 2015, which is the same as the FY 2014 level of funding for the program, and also request that the Subcommittee reject the Administration's proposal to merge the FGP program into the AmeriCorps program. The National Association of Foster Grandparent Program Directors (NAFGPD) is a membership-supported professional organization who administers 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. Quite frankly Mr. Chairman, we need your help now more than ever. The Administration's FY 2015 Budget Request would cut FGP by $14,896,000 or 14%. This represents a loss of 3,360,000 service

hours, valued at $74,390,000 according to the Independent Sector's 2014 data, to children struggling with language, literacy and other academic skills. Worse than even this funding cut, the Budget Request also proposes moving FGP to the AmeriCorps systems of management and funding.

The Foster Grandparent Program has made efficient use of federal dollars to make real changes in children's lives, doing this effectively for almost fifty years. FGP has thousands of supporting organizations in communities across the country. The program has never been accused of mismanagement or waste, and has garnered respect from both Republicans and Democrats alike. Where is the evidence that FGP and Senior Corps programs will become more effective under the AmeriCorps model? What rigorous evaluation has been done to justify this policy decision? There has been no stakeholder input solicited by this Administration or any discussions with either CNCS or the Administration that FGP and the Senior Corps programs needed to be completely restructured. This policy decision is a complete surprise and I on behalf of the larger FGP community want to be on record stating that the Administration's FY 2015 budget proposal for FGP and the other Senior Corps programs is a bad idea.

Under this budget proposal, FGP programs would be folded into AmeriCorps in FY 2015 and then in FY 2016 would compete against the larger AmeriCorps program for a three-year funding grant. To accomplish this transition in FY 2015, the President's Budget Proposal would allocate less funding for FGP and transition less volunteers than those that currently serve. Under the new plan, "AmeriCorps Foster Grandparents" would be required to serve only 450 hours, less than half the current 1,044 hours of a standard 20 hour week. This means fewer hours of service given to children who desperately need help.

NAFGPD is also very concerned that many Foster Grandparents' long years of service to children do not fit well into the AmeriCorps model. It is assumed that ¼ time AmeriCorps members can serve a maximum of eight years, but many Foster Grandparents serve much longer than that – 10, 15, 20, or even 25 years. Their abilities with children tend to improve over time, with more experience and more training. Reducing their years of service would cause the Foster Grandparent Program to lose effective, seasoned volunteers, and would cause schools and other volunteer stations to lose the continuity of long-term volunteers.

I'd also like to note that Foster Grandparent Programs represent 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. Foster Grandparent Programs have forged partnerships with thousands of community organizations that value and support the Foster Grandparents' service. FGP 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. These communities and organizations are unlikely to continue their support if they learn that Foster Grandparents' service hours will be drastically reduced and that their local Foster Grandparent Program would need to compete with AmeriCorps programs that have very different priorities.

Furthermore, putting Foster Grandparent Programs into a general AmeriCorps competition would put all of our current programs at risk. The FY 2015 CNCS budget justification material states, "In FY 2015, AmeriCorps grants will be awarded to current Foster Grandparent Program grantees for one year only. In subsequent years, AmeriCorps Foster

Grandparent Program grantees will be able to compete for three-year grant periods in the broader AmeriCorps program." Expecting current Foster Grandparent Program grantees to compete with the entire AmeriCorps pool doesn't make sense, and seems like a deliberate attempt by the Administration to "bury" current FGP programs.

Some people might say that FGP supporters are reluctant to change, but some things do not and should not change with time. The bond between FGP volunteers and the children they serve is one of them. FGP has been creating meaningful, life-changing bonds between seniors and children for almost fifty years. This has been incredibly effective for these children, and will continue to be – if FGP is allowed to continue as it is currently structured.

In short, NAFGPD strongly opposes any budget proposal which would result in fewer hours of service given to children who have special or exceptional needs, who are at academic, social, or financial disadvantage. NAFGPD also doesn't support the President's Budget Request for RSVP or SCP, the other two Senior Corps programs at CNCS. The Senior Corps programs and their respective Associations are united in their opposition against this Budget Request.

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. NAFGPD believes that you and your colleagues in Congress appreciate what our senior volunteers accomplish every day in communities across the country.

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. From the 20 original programs based totally in institutions for children with severe mental and physical disabilities, FGP now comprises 313 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: THE VOLUNTEERS In FY2012, 28,250 FGP volunteers, of whom 1,000 were veterans, contributed 23.7 million hours of service through approximately 10,000 local agencies. Foster Grandparents served 215,700 children and youth with exceptional needs, including mentoring 110,300 children. Of the $110,300 children mentored, 3,038 children were from military families and almost 6,600 were children with incarcerated parents. The value of this service is over $500 million and represents more than a four-fold return on the federal dollars invested in FGP. 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. 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. Through their service, our FGP 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 through experience.

FGP: THE CHILDREN 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.

Jim Maddy, President and CEO
Association of Zoos and Aquariums
Testimony – House Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Thank you Chairman Kingston and Ranking Member DeLauro for allowing me to submit testimony on behalf of the nation's 213 U.S. AZA-accredited zoos and aquariums. Specifically, I want to express my support for the inclusion of $38.6 million for the Institute of Museum and Library Services' (IMLS) Office of Museum Services in the FY2015 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Founded in 1924, the Association of Zoos and Aquariums (AZA) is a nonprofit 501c(3) organization dedicated to the advancement of zoos and aquariums in the areas of conservation, education, science, and recreation. AZA-accredited zoos and aquariums annually see more than 182 million visitors, collectively generate more than $21 billion in annual economic activity, and support more than 204,000 jobs across the country. Over the last five years, AZA-accredited institutions supported more than 4,000 field conservation and research projects with $160,000,000 annually in more than 100 countries. In the last 10 years, AZA-accredited zoos and aquariums formally trained more than 400,000 teachers, supporting science curricula with effective teaching materials and hands-on opportunities. School field trips annually connect more than 12,000,000 students with the natural world.

Aquariums and zoological parks are defined by the "Museum and Library Services Act of 2003" (P.L. 108-81) as museums. The Office of Museum Services awards grants to museums to support them as institutions of learning and exploration, and keepers of cultural, historical, and

scientific heritages. Grants are awarded in several areas including educational programming, professional development, and collections management, among others.

The nation's AZA-accredited zoos and aquariums, even while facing budget limitations, are thriving during these uncertain economic times. As valued members of local communities, zoos and aquariums offer a variety of programs ranging from unique educational opportunities for schoolchildren to conservation initiatives that benefit both local and global species. The competitive grants offered by the IMLS Office of Museum Services ensure that many of these programs, which otherwise may not exist because of insufficient funds, positively impact local communities and many varieties of species.

For example, with a 2013 Museums for America - Collections Stewardship grant the Toledo Zoo will obtain new life support systems for an interactive visitor touch tank containing invertebrates and another holding sharks and stingrays. The exhibits provide multi-sensory experiences that connect people with animals, while the systems ensure the animals are properly cared for. Through its 2012 Museums for American grant, the Birmingham Zoo supported its Africa Zoo School program, which is serving 1,200 students over two years. Partnering with Birmingham City School, seventh-grade students from low-performing schools attend a week-long "Zoo School" session, where they learn about the crisis of the elephant species' survival in Africa, the cultures of people in Africa, and the scientific and engineering research involved in sustaining these populations. Finally, a 2011 Museums for America grant enabled The National Aquarium in Baltimore to create a more robust volunteer program by

developing and testing new techniques to attract, train, engage, and retain a new generation of more diverse volunteers.

Unfortunately, current funding has allowed IMLS to fund only a small fraction of all highly-rated grant applications. Despite this funding shortfall, zoo and aquarium attendance has increased and the educational services zoos and aquariums provide to schools and communities are in greater demand than ever. Zoos and aquariums are essential partners at the federal, state, and local levels in providing education and cultural opportunities that adults and children may otherwise never enjoy.

As museums, zoos and aquariums share the same mission of preserving the world's great treasures, educating the public about them, and contributing to the nation's economic and cultural vitality. Therefore, I strongly encourage you to include $38.6 million for the Institute of Museum and Library Services' Office of Museum Services in the FY2015 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you.

Transmitted by Jonathan Nurse, Director of Government Relations, IDSA

The Infectious Diseases Society of America's (IDSA) Fiscal Year 2015 Funding Statement Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
March 25, 2014

On behalf of the Infectious Diseases Society of America (IDSA), I am pleased to provide testimony in support of the U.S. Department of Health and Human Services (HHS) components that work to prevent, detect and treat infectious diseases (ID). IDSA represents more than 10,000 ID physicians and scientists devoted to patient care, prevention, public health, education, and research. IDSA recommends increased Fiscal Year (FY) 2015 federal investments in public health and biomedical research to save lives, contain health care costs, and promote economic growth. More specifically, IDSA encourages the Subcommittee to provide a program level of $7.8 billion for the Centers for Disease Control and Prevention (CDC) as well as $32 billion for the National Institutes of Health (NIH). IDSA is particularly supportive of the proposed CDC Detect and Protect Against Antibiotic Resistance Initiative and requests that it be fully funded at $30 million. We ask that the Subcommittee also advance FY 2015 appropriations that reflect the national security and public health significance of the Biomedical Advanced Research and Development Authority (BARDA). All of these investments are a necessary part of a federal strategy to decrease the incidence and fatality of infectious diseases in our population.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The ID community's partnership with the CDC has never been more necessary, as we work to address the public health crisis of rising antibiotic resistance while continuing efforts in other important areas such as increasing immunization rates and slowing the spread of HIV.

Last fall, CDC issued a report, *Antibiotic Resistance Threats in the United States, 2013* that for the first time ranked and detailed the threats posed by antibiotic resistant microbes. Conservative estimates reveal that more than two million Americans suffer antibiotic resistant

infections each year, which result in approximately 23,000 deaths. The actual numbers are likely far higher, as our surveillance and data collection capabilities cannot yet capture the full disease burden. These infections due to antibiotic resistant microbes cost tens of billions of dollars to the U.S. health care system annually, and the problem is worsening. The CDC recommended actions in four core areas to address the problem, including prevention, tracking, antibiotic stewardship, and development of new antibiotics and rapid diagnostics. The CDC has proposed FY 2015 activities in each of these areas.

National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)

The NCEZID plays a leading role in CDC efforts to address antibiotic resistance. As such, we ask that it be provided at least the $445 million requested by the Administration, including at least $30 million for the Detect and Protect Against Antibiotic Resistance Initiative. This initiative would establish regional prevention collaboratives to implement best practices for antibiotic use and infection prevention, create a detection network of five regional labs to speed up identification of the most concerning threats, improve antibiotic stewardship, and develop an isolate library that will help facilitate the development of desperately needed new antibiotics and diagnostics. The initiative directly addresses the recommended actions from the CDC 2013 report. The CDC projects that over five years the initiative will lead to a 50% reduction in health-care associated *Clostridium difficile* (*C. diff*), 50% decline in health-care associated carbapenem-resistant Enterobacteriaceae (CRE), 30% decline in invasive methicillin-resistant *Staphylococcus aureus* (MRSA), 30% decline in health-care associated drug-resistant *Pseudomonas* sp., and 25% reduction in drug-resistant *Salmonella* infections. These bacteria claim thousands of lives annually. CRE, for one, have become resistant to all or nearly all

currently available antibiotics. Further, nearly 50% of those who develop bloodstream infections from CRE die.

IDSA also supports the proposed $14 million increase for the National Healthcare Safety Network (NHSN), which would increase the number of healthcare facilities reporting antibiotic use and antibiotic resistance data and would develop and evaluate new infection prevention strategies.

IDSA thanks Congress for funding the Advanced Molecular Detection (AMD) initiative in FY 2014 and recommends that at least $30 million be allocated for it in FY 2015. AMD strengthens CDC's molecular sequencing tools and bioinformatics capacity to more rapidly and accurately detect infectious diseases and resistance.

IDSA applauds the Administration for launching a Global Health Security Agenda, which would strengthen the capacity of nations to prevent, detect and slow the spread of infectious diseases across borders, simultaneously reducing threats to the United States. We ask that you provide the initiative with funding allocated in the FY 2015 PBR.

National Center for Immunization and Respiratory Diseases (NCIRD)

We know that vaccines are among the most cost-effective clinical preventative services. However, according to the February 2014 CDC Morbidity and Mortality Weekly Report (MMWR), adult immunization rates remain low for most routinely recommended vaccines and considerably short of Healthy People 2020 targets. Each year in the United States, more than 40,000 adults die from illnesses that are preventable through vaccination.

IDSA opposes the $51 million program level reduction to the CDC Immunization Grant Program (Section 317) contained in the PBR. Although the Affordable Care Act requires insurers to cover immunizations, this alone will not guarantee access or utilization. The Section

317 funds are critical to help providers obtain and store vaccines; establish and maintain vaccine registries; as well as to educate providers and the public about vaccine recommendations, effectiveness and safety; and promote universal vaccination of health care workers.

CDC plays a critical role in seasonal and pandemic influenza preparedness and response, including conducting important surveillance activities that better inform response efforts and providing public communications regarding influenza prevention and treatment. Lack of sufficient funding for these efforts could lead to an increased incidence and severity of influenza, as well as increased hospitalization costs and mortality. In the long term, continuously funded efforts will be more cost-effective than the periodic emergency supplemental funding approach that historically has been used to fund such efforts. IDSA supports the proposed FY 2015 increase of $15 million for these efforts.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, we believe that the National Institute of Allergy and Infectious Diseases (NIAID) should be funded at least at the $4.58 billion requested by the Administration in the FY 2014 PBR. Nearly flat-funding NIAID limits investment in new research and serves as a disincentive for young people to pursue ID research careers so critical to the new discovery of new therapies, new diagnostic approaches, and new preventive strategies.

The NIAID recently began funding a new clinical trials network focused on antibiotic-resistant bacterial infections. With sufficient funding, the new research network/infrastructure will conduct critical studies to address antibiotic resistance as well as begin to answer questions that will help fill the nearly empty antibiotic R&D pipeline. Severe economic disincentives have caused a mass exodus of private companies from the antibiotics market, making federally funded

research in this area more critical than ever. An IDSA report issued in April 2013 identified only seven new drugs in development for the treatment of infections caused by multidrug-resistant Gram-negative bacilli (GNB). We applaud NIAID's initiative in launching the new network. However, IDSA recommends increased investment in this area.

A recent IDSA report, *Better Tests, Better Care: Improved Diagnostics for Infectious Diseases*, highlights the need for advancements in diagnostic tools to address bacterial, viral and fungal infections and recommends strengthened NIAID funding for this priority. Faster, more accurate diagnostics lead to better treatments and improved patient outcomes. In addition, new diagnostics are needed to identify patients with highly contagious illnesses so that containment and prevention measures can be undertaken. Diagnostics can improve physicians' ability to discern which infections need antibiotics, and thereby help reduce the unnecessary use of antibiotics that drives the development of antibiotic resistance.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)

Biomedical Advanced Research and Development Authority (BARDA)

ASPR plays a key leadership role in coordinating federal efforts to sufficiently protect the nation from biothreats, pandemics and emerging infections. IDSA recommends increased funding for BARDA, which has been flat-funded for several years. Additional investment in medical countermeasure development is critical to prepare for both intentional attacks and naturally emerging infections. BARDA is a critical source of funding for public-private collaborations for antibiotic, diagnostic and vaccine R&D.

Thank you for the opportunity to submit this statement on behalf of the nation's ID physicians and scientists. We rely on strong federal partnerships to keep Americans healthy and urge you to support these efforts. Please forward any questions to jnurse@idsociety.org.

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Written Statement of

the American Psychiatric Association

to the House Appropriations Subcommittee on

Labor, Health & Human Services and Education

March 21, 2014

I. Introduction & Background

American Psychiatric Association (APA), a medical specialty society representing approximately 35,000 psychiatrists, is pleased to present its recommendations regarding Fiscal Year 2015 (FY15) appropriations for Graduate Medical Education (GME), the National Institute of Mental Health (NIMH), the National Institute on Drug Abuse (NIDA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and Indian Health Services.

APA recognizes the Subcommittee faces difficult decisions in a constrained budget environment; however, a continued commitment to critical programs supporting physician workforce development should remain a high priority. Strong, sustained funding of mental health and substance use disorder services is necessary to ensure the overall health of Americans and the nation's economic prosperity. Federal investment is vital for the National Institutes of Health (NIH) to sustain its mission of improving health through medical science breakthroughs and maintain international leadership in science and biomedical research.

Impact of Budget Cuts on America's Health

Continued austerity will have a tremendous impact on the nation's medical schools and teaching hospitals and the patients they serve. Deficit reduction proposals to cut Medicare GME support, including decreases in Indirect Medical Education (IME) payments threaten access to critical services unavailable elsewhere and reduce physician training at a time when patient needs are increasing. For the next 18 years, 10,000 people a day will turn 65, creating a significant increase in demand for psychiatric care and other medical specialties. The continuing 2 percent sequestration cut in Medicare reimbursements jeopardizes these institutions' ability to provide critical patient care services such as

psychiatric units often unavailable elsewhere in communities. Reductions in physician payments will further restrict access to community-based care.

The nation's supply of pediatricians and pediatric specialists depend on physician training programs at the nation's children's hospitals. Training programs are supported by the Children's Graduate Medical Education program (CHGME). Reductions to CHGME jeopardize the supply of pediatricians and pediatric specialists that all children need. APA opposes Administration's proposed 67 percent cut to $88 million for CHGME, from FY14's $177 million funding level. APA asks Congress to continue its support for this vital program in FY15 with an allocation of $185 million.

II. Importance of Federal Investments in Biomedical Research

APA strongly advocates for federal investments to detect and discover treatments for mental illnesses and substance use disorders. The National Institute of Mental Health (NIMH) conservatively estimates the total costs associated with serious mental illnesses, disorders that are severely debilitating and affect about 6 percent of the adult population, to be in excess of $300 billion per year ($193 billion loss of earnings, $100 billion heath care expenditures and $24.3 billion disability benefits). The costs associated with mental illnesses stem from both the direct expenditures for mental health services and treatment (direct costs) and from expenditures and losses related to the disability caused by these disorders (indirect costs). Indirect costs include public expenditures for disability support, lost earnings among people with serious mental illness and burden on families. More specific diagnostic tools, earlier treatment, developing medications with fewer side effects and the potential of genomic-sensitive treatments are priorities for NIMH. Gender and ethnic differences exist in the development, clinical course, and outcomes of bipolar disorder and schizophrenia. We need to understand the reasons for these disparities and develop methods of addressing them. Investment in the NIH and the Brain

Research through Advancing Innovative Neurotechnologies Initiative (BRAIN) will advance this knowledge.

Drug abuse and addiction have negative consequences for individuals, families and for society. Estimates of the total overall costs of substance abuse in the United States, including productivity and health- and crime-related costs, exceed $600 billion annually. This includes approximately $181 billion for illicit drugs, $193 billion for tobacco, and $235 billion for alcohol. As staggering as these numbers are, they do not fully describe the breadth of destructive public health and safety implications of substance use and addiction, such as family disintegration, loss of employment, failure in school, domestic violence, and child abuse. The National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) are tasked with developing and implementing new treatments for addiction and identifying the causes and contributors of addiction. The need has never been greater for support of research on opiate addiction, prevention of prescription drug abuse and the impact of alcohol on liver disease (source: National Survey on Drug Use and Health, SAMHSA).

III. Importance of Federal Investments in Services

Seventy five percent of states reported a substantial increase in demand for community-based mental health care services. This higher demand comes at a time when states are closing psychiatric hospitals and clinics and reducing support for community-based mental health services. SAMHSA's Center for Mental Health Services (CMHS) funds important programs including: state block grants, suicide prevention, homelessness prevention, jail diversion for people with mental illness, and services for children and the elderly. Due to the economic downturn, states have been forced to cut mental health care funding by a total of nearly $4.6 billion since 2008 (source: NAMI). SAMHSA's Center for Substance Abuse Treatment (CSAT) and Center for Substance Abuse Prevention (CSAP) provides millions to states in block grants for flexibility in responding to the particular needs in each state. The APA would

like to draw the Committee's attention to SAMHSA's Minority Fellowship Training program which underpins training for psychiatrists and other mental health care providers in underserved areas of the United States. The Minority Fellowship Training program promotes ethnic diversity and supports access to care for vulnerable populations.

APA Requests

APA requests that NIH receive at least $32 billion in FY15 as the next step toward a multi-year increase in our nation's investment in medical research. While the Consolidated Appropriations Act of 2014 included an increase for the National Institutes of Health (NIH), this increase did not reinstate all of the funds cut by sequestration in FY13 nor did it restore inflation's erosion of purchasing power over the past decade. We hope FY15 represents a first step toward restoring our nation's preeminence in medical research.

For the Center for Mental Health Services (CMHS) under SAMSHA, APA supports an appropriation of $10 million for CMHS' Minority Fellowship Training program to respond to workforce needs. As Congress considers funding of the "Now is the Time Initiative" within CMHS, APA requests that a wide variety of early detection programs be allowed to enter a competitive grant program for these funds. CMHS' FY14 Omnibus Appropriations measure included a five percent set-aside in the Mental Health Block Grant for the promulgation of evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders. APA supports this CMHS-NIMH collaboration and urges it to quickly implement its task. The APA remains concerned over the rise in addiction and abuse of opioid medications. APA strongly encourages the training of, and use of, more physicians, for opioid-dependence treatment particularly psychiatrists who are specially trained in the use of Suboxone and Buprenorphine. These medications act as "opioid antagonists" and can assist in the patient's supervised withdrawal from opioids. As a partner organization in two clinical mentoring

and education initiatives funded by SAMHSA: Physicians "Clinical Support System-Buprenorphine (PCSS-B) and the Prescribers' Clinical Support System- Opioid Therapies (PCSS-O), APA is advancing clinical expertise APA has produced a series of webinars focused on the use of opioid therapies for treatment of opioid dependence and the safe use of opioids in the treatment of chronic pain. These free webinars are available for psychiatrists, other physicians, residents, and other interested clinicians at www.pcssb.org/educational-and-training-resources/special-topics

Finally, APA supports a 10 percent ($420 million) increase in clinical services funding for the Indian Health Service, in FY15 in keeping with the recommendation from the Friends of Indian Health Coalition. Native American youth have the highest suicide rate in the U.S., 1.7 times higher than the rest of the population. Increasing access to services will get medical care to at-risk teenagers before they take their lives.

To continue to improve our nation's health and economic well-being, America needs to accelerate and increase its investment in medical research, the physician workforce, and care for those with mental health and substance use disorders and their families. American Psychiatric Association appreciates the opportunity to submit its statement on FY15 funding priorities to the Subcommittee.

Thank you.

Written Testimony by John Bayouth, Ph.D. on behalf of the American Association of Physicists in Medicine (AAPM) on

FY 2015 Appropriations for the National Institutes of Health

Submitted March 28, 2014, for the Record to the

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

Committee on Appropriations

United States House of Representatives

The AAPM recommends a funding level of **$32.0 billion for NIH** and **$397 million for the NIBIB** in fiscal year (FY) 2015.

Thank you for providing the AAPM with the opportunity to submit written testimony on fiscal year 2015 funding for the National Institutes of Health (NIH). The AAPM is the premier organization in medical physics, a broadly based scientific and professional discipline encompassing physics principles and applications in biology and medicine whose mission is to advance the science, education and professional practice of medical physics.

Looking back to fiscal year 2004, NIH funding stood at $27.8 billion in nominal dollars. A decade later, NIH now stands at $30.0 billion – meaning that our engine for medical

breakthroughs in the U.S. has grown a total of just over 5% over the past eleven years, or at an annualized rate of 0.5%. While we acknowledge that the Subcommittee is not responsible for the larger budget constraints, the annualized growth rate for NIH over the past decade continues to not reflect that of an economy whose future depends on innovation, technological breakthrough, and lower healthcare costs made possible by research discoveries.

NIH Director Francis Collins, M.D., Ph.D. stated before the Subcommittee on March 5, 2013 that other nations are "ramping up their support of biomedical research because they've read our playbook." Indeed, unlike the U.S., both emerging and developed economies continue to prioritize public funding for medical research and development. China alone is committing an average of $60 billion per year to biotechnology over the next five years – double the budget of the NIH. If NIH had continued its historical annual rate of growth (6.5%) from the 1960s to 1998 after the "doubling," it would now be supported at $46.7 billion a year. Even a smaller but sustainable level of 4% annual growth since 2004 would put NIH funding at $38.5 billion today.

It is time to move NIH back into meaningful positive direction, ensuring that it can sustain and grow the number of multi-year investigator-initiated research grants, the foundation of our nation's biomedical research enterprise. We ask that the Subcommittee prioritize NIH even within the statutorily imposed budget caps, and begin reinvigorating medical research with an appropriation of $32.0 billion in Fiscal Year 2015.

AAPM Testimony FY2015 NIH and NIBIB Funding

The National Institute of Biomedical Imaging and Bioengineering as an Incubator and Supplier of New Technologies

Since the 1980s, many clinical and technological advances in CT, MRI, PET imaging, and image-guided therapies have been developed through funding from the National Institute for Biomedical Imaging and Bioengineering (NIBIB). Radiology research is truly an interdisciplinary science, bringing together physicians, physicists, mathematicians, chemists, computer scientists, physiologists and others from numerous scientific fields. This strong and diverse research pipeline has helped solidify the U.S as the world leader in the basic research, development, and commercialization of advanced medical imaging technologies. It also makes the investment in NIBIB's research particularly valuable, as there are three distinct outputs from NIBIB research:

1) ***bench-to-bedside imaging tools*** that help medical professionals diagnose, treat, and monitor a wide array of diseases and conditions, saving millions of lives each year;
2) ***bench-to-bench interdisciplinary research tools*** that have given thousands of researchers in other fields game-changing new ways to tackle the diseases that they study; and
3) ***a pipeline for commercial imaging products,*** as medical imaging devices represent one of the nation's healthiest export industries, providing tens of thousands of high-skilled jobs across the country and adding positively to the nation's gross domestic product.

Despite its small stature ($327 million in FY 2014), the NIBIB is especially important as the federal incubator for innovation in the rapidly moving field of medical imaging. Given its three-

AAPM Testimony FY2015 NIH and NIBIB Funding

legged return on investment as a supplier of new technologies for patient care, a developer of game-changing new technologies for scientists in all fields, and a pipeline for a key domestic sector, we request a shift in the NIH portfolio for greater investment in imaging R&D.

A global benchmark for R&D spending for an innovation economy is 3% of GDP. We recommend that the NIH portfolio begin to be readjusted in FY2015 to allow for this same investment in biotechnology, bioengineering and biomedical imaging R&D, increasing the proportion of funding to NIBIB from the current 1.10% of the NIH budget to 3.0% over the next five years. This budget path and reallocation across NIH would call for a $70 million increase for NIBIB in FY2015, setting the budget for NIBIB at $397 million.

STATEMENT BY AMERICAN HEART ASSOCIATION
MARIELL JESSUP, M.D., PRESIDENT
202-785-7900; claudia.louis@heart.org; 1150 Connecticut Ave, NW, DC 20036

FY 2015 LABOR-HHS-EDUCATION APPROPRIATIONS: NIH, CDC, HRSA

Although great progress has been made in prevention and treatment of cardiovascular disease, including stroke, there is no cure and CVD remains America's No. 1 killer, costing a projected $315 billion in medical expenses and lost productivity each year. Stroke, alone, is our No. 4 killer, costing an estimated $37 billion a year. Both remain major causes of disability.

Nearly 84 million U.S. adults suffer from some form of CVD. It is projected that by the year 2030, more than 44% of U.S. adults will live with CVD at a cost exceeding $1 trillion annually. So, it is disturbing that CVD research, prevention and treatment remain disproportionately underfunded with no sustained and stable funding from the National Institutes of Health. NIH is key for the U.S. to mount an ongoing and effective crusade against these devastating diseases.

We appreciate Congress' and the Administration's partial stay of sequestration. These cuts jeopardize the health of tens of millions of CVD sufferers and weaken our fragile economy and erode our global leadership in medical research. We challenge Congress to appropriate stable and sustained funding for CVD research, prevention and treatment. NIH funding is not only important for the health of our Nation, but also supports our economy through research-related employment opportunities it provides.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Research that could move us closer to a cure for heart disease and stroke goes unfunded. Congress must capitalize on 50 years of progress or our nation will pay more in lives lost and health care costs. Our recommendations tackle the topics in a fiscally responsible way.

Capitalize on Investment for the National Institutes of Health (NIH)

AHA is disappointed Congress did not fully restore sequester cuts for NIH in Public Law 113-76. NIH funded studies help prevent and cure disease, revolutionize patient care, drive economic growth, advance innovation, and sustain U.S. leadership in pharmaceuticals and biotechnology. NIH is the world's leader of basic research—the starting point for all medical progress and an indispensable Federal government role that the private sector cannot fill. The U.S. is in jeopardy of losing our competitive edge in scientific research.

In addition to improving health, NIH creates a solid return on investment. In FY 2012, NIH supported 400,000 U.S. jobs and produced nearly $60 billion in new economic activity. Every $1 in NIH funding produced $2 in economic activity in 2007. Yet, for the past decade, the NIH's budget has not kept pace with medical research inflation, resulting in more than a 20% loss in purchasing power. Such reductions, along with only a 50% restoration of sequester cuts, have occurred during a time of remarkable heightened scientific opportunity and when other countries have been increasing investment in science—some by double digits. These cutbacks have also demoralized early career investigators who, sadly, may leave and never return to research. We cannot afford to lose one of our Nation's most valuable resources—an innovative biomedical research workforce.

***American Heart Association Advocates*:** We ask Congress to appropriate $32 billion for NIH to restore sequester cuts, provide for modest growth, and advance CVD research.

Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment

Declining death rates from CVD is directly related to NIH research, with scientists on the verge of discoveries that could lead to groundbreaking treatments and even cures. In addition to saving lives, NIH research is cost-effective. For example, the first NIH tPA drug trial resulted in a 10-year net $6.47 billion drop reduction in stroke health care costs.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)

CVD death rates have greatly declined, with much of the reduction traced to research emanating from the NHLBI. Stable and sustained NHLBI funding is key to capitalize on investments that have led to major discoveries. For example, 10% of genetic changes leading to severe congenital heart disease are new and not passed down by a parent; people who maintained ideal health had better brain function in mid-life; digestive system bacteria may cause red meat to raise two chemicals linked to CVD; and post-traumatic stress disorder may be a heart disease risk factor. Sustained funding will allow robust implementation of priority CVD strategic plan initiatives.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)

An estimated 795,000 Americans will suffer a stroke this year and more than 129,000 will die. Many of the 7 million survivors face grave physical and mental disabilities and emotional trauma. In addition to the physical and emotional toll, stroke costs an estimated $37 billion in medical expenses and lost productivity each year. Moreover, the future looks grim. A study projects that direct costs of stroke will triple between 2010 and 2030.

Stable and sustained NINDS funding is needed to capitalize on investments, including one showing aggressive medical treatment is better than stents in preventing a second stroke, and to advance the BRAIN Initiative. More resources are required to facilitate the NIH Stroke Trials Network and other priorities in stroke prevention, treatment and recovery research. They include: hastening translation of preclinical animal models into clinical studies; preventing vascular cognitive damage; expediting comparative effectiveness research trials; developing imaging biomarkers; refining clot-busting treatments; achieving robust brain protection; targeting early stroke recovery; and using neural interface devices.

American Heart Association Advocates: We recommend that NHLBI be funded at $3.2 billion and NINDS at $1.7 billion for FY 2015.

Increase Funding for the Centers for Disease Control and Prevention (CDC)

Prevention is the best way to promote good health and reduce the costs of heart disease and stroke. Yet, proven prevention approaches are not implemented due to limited funds. We applaud Congress for providing in P.L. 113-76 the Division for Heart Disease and Stroke Research with a much needed boost. In addition to supporting research and evaluation and developing a surveillance system, the DHDSP administers Sodium Reduction Communities and the Paul Coverdell National Acute Stroke Registry. DHDSP, with the Centers for Medicare and Medicaid Services, implements Million Hearts™ to prevent 1 million heart attacks and strokes by 2017.

DHDSP runs WISEWOMAN, serving uninsured and under-insured, low-income women ages 40 to 64. It helps them from becoming heart disease and stroke statistics by offering preventive health

services, referrals to local health care, and tailored lifestyle programs to promote lasting behavioral change.

American Heart Association Advocates: We join with the CDC Coalition in asking for $7.8 billion for CDC's program level. AHA requests $130.188 million for the DHDSP to sustain its participation in the State Public Health Actions to Prevent and Control Diabetes, Heart Disease, Obesity and Associated Risk Factors and Promote School Health and $37 million for WISEWOMAN. We ask for $3 million for Million Hearts™ to better control blood pressure.

Restore Funding for Rural and Community Access to Emergency Devices (AED) Program

About 90% of cardiac arrest victims die outside of a hospital. Yet, early CPR and use of an automated external defibrillator can more than double survival. Communities with full AED programs have survival rates near 40%. HRSA's Rural and Community AED Program awards competitive grants to states to buy AEDs, tactically place them, and train lay rescuers and first responders in their use. Nearly 800 patients were saved from August 1, 2009 to July 31, 2010. But scarce resources let only 22% of approved applicants in 6 states receive funds in FY 2013.

***American Heart Association Advocates*:** We ask for a FY 2015 appropriation of $8.927 million to return this life-saving AED program to FY 2005 levels when 47 states were funded.

CONCLUSION

Cardiovascular disease, including stroke, still wreak a deadly, disabling and costly toll on Americans. Our recommendations for NIH, CDC and HRSA will save lives and slash escalating health care costs. We challenge Congress to carefully study our requests that signify a wise investment for our country and for the health and well-being of this and future generations.

Name: Jan Fortney

Title: Parent & Guardian of an Adult with Intellectual/Developmental Disabilities

Institutional Affiliation: Friends & Families of Care Facility Residents (FF/CFR) and Conway Human Development Center Parent Association

March 23, 2014

To: House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Re: 2015 Budget – Department of Health and Human Services

Dear Appropriations Subcommittee Members:

Thank you for this opportunity to submit Testimony for the Record regarding the 2015 Budget for the Department of Health and Human Services and the elimination of funding of harmful programs under this budget.

I am the mother and guardian of an adult daughter, age 39, whose home is a state-operated, Medicaid-certified congregate care facility in Conway, Arkansas. Kim has been developmentally disabled since birth. Her cognitive level of understanding is approximately 1 year and 10 months. Kim lived in our home until she was 18 ½ year old, and then her needs seemed to change. She needed more activity and independence in her life. Kim has thrived at the Conway Human Development Center for over 20 years now, and we are very much still a part of her life.

I serve as Secretary of our statewide parent/guardian group and as President of our local parent association where we work together to support good public policies for people with disabilities. My testimony today is regarding the Department of Health and Human Services

2015 Budget. A partial list of federal programs included in the DHHS appropriations which I find offending are:

1) National Council on Disability (NCD);
2) Administration on Intellectual and Developmental Disabilities (AIDD); and
3) DD Act Programs, which include:
   - State Developmental Disabilities Councils;
   - Protection & Advocacy Organizations; and
   - University Centers of Excellence on Developmental Disabilities

These federally funded programs' actions promote public policies that are dangerous to individuals like my daughter! They publically and actively use their funds to promote the down-sizing and closure of facilities that serve the most vulnerable individuals our society has to care for. These "facilities" are "home" to so many people with diverse special needs! My daughter loves her home and her life! She is very well cared for, and still has the opportunity to participate in her local community. These aggressive federally funded programs try to force deinstitutionalization of people with severe, profound, and extreme forms of intellectual and developmental disabilities!

Our state's Protection & Advocacy Organization (Disability Rights Center) has publically asked for the closure of our Intermediate Care Facilities (ICFs) that have historically proven to be very good and sound programs. Just this month the DRC has asked our state not to spend any more money to support the vital life sustaining centers (ICFs). Also, DRC has filed class action law suits in the past, including our loved ones with profound intellectual disabilities as part of those law suits and without our knowledge! This should be illegal in the first place!! There needs to be a law against it!! The courts have already ruled that the legal guardian is the one to

make decisions when it comes to those they represent. However, we are not given the chance to "opt out" of those lawsuits on behalf of our loved ones! This is just an example of one of the programs and the harmful activities they produce. We have many more examples!

The nation's service system for individuals with severe cognitive developmental disabilities has been weakened by the aggressive deinstitutionalization activities of the programs mentioned above.

I would ask that you consider the following:

- ***cease giving federal funds to programs that undermine, weaken and eliminate licensed Medicaid - certified residential facilities for persons with developmental disabilities;***
- ***cease giving federal funds to support the deinstitutionalization activities of these programs; and***
- ***cease providing federal funds (grants) to organizations which have worked and are working to eliminate congregate care facilities for persons with developmental disabilities.***

Thank you for the opportunity to comment.

Respectfully submitted,

Jan Fortney

Jan Fortney

cc: Arkansas Congressional Delegation

Families & Friends of Care Facility Residents

National Parent-Guardian Network

Written Testimony by the Academy of Radiology Research on FY 2015 Appropriations for the National Institutes of Health Submitted March 28, 2014, for the Record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies Committee on Appropriations United States House of Representatives

The ARR recommends a funding level of $32.0 billion for NIH and $397 million for the NIBIB in fiscal year (FY) 2015

Thank you for providing the Academy of Radiology Research with the opportunity to submit testimony on fiscal year 2015 funding for the National Institutes of Health (NIH). The imaging research community deeply appreciates the Subcommittee's leadership and support for both the NIH as well as the National Institute for Biomedical Imaging and Bioengineering Research.

After the sequestration cut of 5.1% to the NIH in fiscal year 2013, the Looking back to fiscal year 2004, NIH funding stood at $27.8 billion – which means our engine for medical breakthroughs in the U.S. has grown a total of 5.02% over the past decade, or at a compounded annualized rate of 0.54%. While we acknowledge that the Subcommittee is not responsible for the sequester, the annualized growth rate for NIH over the past decade without sequestration (1.01%) also does not reflect that of an innovation economy.

NIH Director Francis Collins, M.D., Ph.D. recently stated before the Subcommittee on March 5, 2013 that other nations are "ramping up their support of biomedical research because they've read our playbook." Indeed, unlike the U.S., both emerging and developed economies continue to prioritize public funding for medical research and development. China alone is committing an average of $60 billion per year to biotechnology over the next five years – double the budget of the NIH. If NIH had continued its historical annual rate of growth (6.5%) from the 1960s to

1998 after the "doubling," it would now be supported at $46.7 billion a year. Even a smaller but sustainable level of 4% annual growth since 2004 would put NIH funding at $38.5 billion today.

It is time to move NIH back into meaningful positive direction, ensuring that it can sustain and grow the number of multi-year investigator-initiated research grants, the foundation of our nation's biomedical research enterprise. We ask that the Subcommittee prioritize NIH even within the statutorily imposed budget caps, and begin reinvigorating medical research with an appropriation of $32.0 billion in Fiscal Year 2015.

The National Institute of Biomedical Imaging and Bioengineering as an Incubator and Supplier of New Technologies

Since the 1980s, many clinical and technological advances in CT, MRI, PET imaging, and image-guided therapies have been developed through funding from the National Institute for Biomedical Imaging and Bioengineering (NIBIB). Radiology research is truly an interdisciplinary science, bringing together physicians, physicists, mathematicians, chemists, computer scientists, physiologists and others from numerous scientific fields. This strong and diverse research pipeline has helped solidify the U.S as the world leader in the basic research, development, and commercialization of advanced medical imaging technologies. It also makes the investment in NIBIB's research particularly valuable, as there are three distinct outputs from NIBIB research:

1) ***bench-to-bedside imaging tools*** that help medical professionals diagnose, treat, and monitor a wide array of diseases and conditions, saving millions of lives each year;
2) ***bench-to-bench interdisciplinary research tools*** that have given thousands of researchers in other fields game-changing new ways to tackle the diseases that they study; and

3) ***a pipeline for commercial imaging products,*** as medical imaging devices represent one of the nation's healthiest export industries, providing tens of thousands of high-skilled jobs across the country and adding positively to the nation's gross domestic product.

Imaging Research as a Bench-to-Bedside Tool

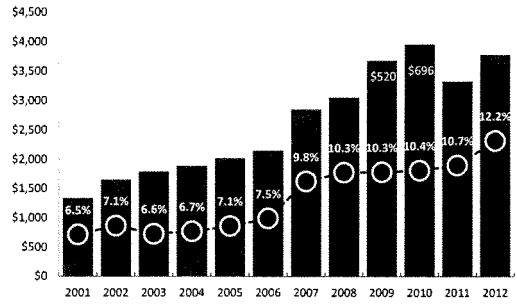
One recent NIBIB-funded discovery - magnetic resonance elastography (MR elastography) - highlights just how radiology researchers are constantly pushing the technological envelope to improve human health. It has long been known that diseased tissue has different mechanical properties that surrounding normal tissue. Specifically, it tends to exhibit a slightly more rigid structure as the disease takes over. Previously, the only way to know that this was occurring was after a biopsy, usually late in the disease's progression. However, radiology researchers knew that if they could use advanced imaging to see these slight biomechanical changes in tissue stiffness, patients and fellow physicians would have a powerful new tool to find tumors earlier than ever before.

NIBIB researchers found that by passing MRI waves through diseased tissue – such as a liver tumor – that they could use new algorithms and gradients to quantitatively measure and image the tissue's rigidity or stiffness. This has tremendous clinical implications, as a number of diseases including liver disease, breast cancer, prostate cancer, and many others can be detected at the earliest stages using MR elastography. Patients suspected of liver disease or cancer may think they are getting "an MRI." However, at places like Mayo Clinic, the radiologists are likely using a new and better imaging test made possible with taxpayer-supported imaging R&D.

Imaging As a Bench-to-Bench Research Tool

Researchers in nearly every field of study at NIH are taking advantage of imaging tools being developed by NIBIB and radiology researchers, using advanced imaging technologies to improve their understanding of disease and accelerate treatments. Demonstrating the scope of the imaging research "toolkit," every NIH Institute funded projects that utilized imaging in FY2011, and nearly half of all Institutes invested 10% or more of their budget to imaging projects in FY2011. Of the 239 NIH Research, Disease and Condition Categorization (RCDC) codes at NIH, imaging projects were funded in 211 (88%) of all diseases being studied. The largest funder was the National Cancer Institute (NCI) at $527m (10%), while other ICs dedicating more than 10% of their budget to imaging projects also align with some of the nation's most pressing health concerns, such as Alzheimer's (NIA – 17%), neurological disorders and stroke (NINDS – 19%), and heart disease (NHLBI – 12%). Across the NIH research enterprise, there is a large and sustained consumer demand for new imaging projects being developed by NIBIB researchers.

Total Amount of Grants Using Advanced Imaging Tools Produced by Radiology Research, and as a Percent of the total NIH Budget, 2001-2012



Imaging Research as a Pipeline for One of America's Strongest Industries

The Department of Commerce identifies medical imaging equipment as one of the country's strongest projected exports for the coming decade. NIBIB research will play a key collaborative role in helping to cement U.S. leadership in the imaging sector by fortifying the pipeline for state-of-the-art imaging equipment. The downstream economic impact from NIBIB research is significant, as GE's MRI division alone supports over 19,000 full-time positions in the U.S.,

while exporting over 1,000 MRI magnets per year from its MRI manufacturing facility in Florence, South Carolina.

Although relatively small at $338 million in FY 2012, the NIBIB is especially important as the federal incubator for innovation in the rapidly moving field of medical imaging. Given its three-legged return on investment as a supplier of new technologies for patient care, a developer of game-changing new technologies for scientists in all fields, and a pipeline for a key domestic sector, we request a shift in the NIH portfolio for greater investment in imaging R&D.

A global benchmark for R&D spending for an innovation economy is 3% of GDP. We recommend that the NIH portfolio begin to be readjusted in FY2014 to allow for this same investment in imaging R&D, increasing the proportion of funding to NIBIB from the current 1.10% of the NIH budget to 3.0% over the next five years. This path to increased imaging R&D would call for a $70 million increase for NIBIB in FY2014.

Testimony by James R. Johnson
Vice President – Workplace Safety Initiatives
National Safety Council

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

March 24, 2014

Chairman Kingston, Ranking Member DeLauro, and Members of the subcommittee, thank you for the opportunity to submit testimony regarding the National Safety Council's workplace safety appropriations priorities. My name is Jim Johnson, and I am Vice President of Workplace Safety Initiatives at the National Safety Council. We are a 100 year-old Congressionally chartered nonprofit safety organization dedicated to saving lives by preventing injuries and deaths at work, in homes and communities, and on the roads through leadership, research, education, and advocacy. Our more than 14,000 member companies represent over 8 million employees at more than 51,000 worksites. Today I am seeking support for $565.01 million for the Occupational Safety and Health Administration (OSHA) and $332.86 million for the National Institute for Occupational Safety and Health (NIOSH), two organizations whose work is vitally important to the mission of safety.

Occupational Safety and Health Administration

The National Safety Council believes that an effective and efficient OSHA is important for the safety of American workers and workplaces. NSC supports stable funding for OSHA that adequately funds all the agency's key functions, including compliance

assistance and support to companies striving for safety excellence, the timely promulgation of regulations to protect America's workers, enforcement actions against companies that fail to comply with OSHA standards, and whistle blower protection for workers.

The Council supports the top line funding level of $565.01 million for the agency included in the President's FY 15 budget request, and we strongly encourage the committee to fund the agency at a minimum of this funding level. While the Council is pleased that OSHA rulemaking and enforcement efforts in FY 14 have been restored to pre-sequester funding levels, we continue to have strong concerns about funding constraints placed on the agency's federal compliance assistance efforts, which are presently funded at $69.4 million, more than 9 percent less than FY 12 enacted levels.

Of special concern to the Council is the impact that reduced compliance assistance funding has had on the agency's Voluntary Protection Programs (VPP). We encourage the committee to include report language recommending that VPP receive no less than $3 million in FY 15.

VPP were created by OSHA in 1982 as a way of recognizing those employers who successfully implement effective safety and health management systems and maintain injury and illness rates below the national average for their industries. Under VPP, company stakeholders establish a relationship with OSHA based on a cooperative partnership. Because of this, approval into VPP is as much a proactive effort as it is

recognition of hard work and effort put in by employers and employees to achieve exceptional records in occupational safety and health.

The pursuit of VPP status has helped many safety professionals encourage their employers' leadership to improve safety management systems by complying with the program's criteria. Organizations with VPP status represent business leaders who have implemented strong safety management systems and demonstrated a commitment to continuous improvement. VPP sites have a Days Away Restricted or Transferred (DART) case rate of 52% below the industry average. The majority of VPP sites have less than 100 employees.

However, despite the success of this program, recent budget constraints have required the agency to slow the growth in the number of new cooperative program participants. Following sequestration in FY 13, OSHA only reapproved sites that could be visited through local travel. As it stands, OSHA is not scheduling new VPP site approvals until a region's backlog of re-approvals of existing VPP facilities is eliminated. Minimum funding at a level of at least $3 million will ensure that OSHA has the resources necessary to address the backlog of re-approvals of existing VPP facilities and to begin to approve new VPP sites.

National Institute for Occupational Safety and Health

Funding NIOSH at the FY 14 funding level of $332.86 million at a minimum, and preserving the FY 14 level of $24 million for the Institute's Agriculture, Forestry and

Fishing (AgFF) Sector Program and $27.5 million for the Education and Research Centers (ERCs), is essential to ensuring that NIOSH can fulfill its mission of saving lives and preventing injuries.

Finally, I would like to focus on the important role that NIOSH programs play in reducing workplace injuries and fatalities. NIOSH's primary responsibility is to conduct research and make recommendations for the prevention of work-related injuries and illnesses. NIOSH works to ensure the health and safety of the American workforce through research, education and training. It is not a regulatory agency, and can only issue recommendations for health and safety standards. The Council is disheartened to see the President's budget request again target the Institute's Agriculture, Forestry and Fishing (AgFF) Sector Program and Education and Research Centers (ERCs) by eliminating their budget.

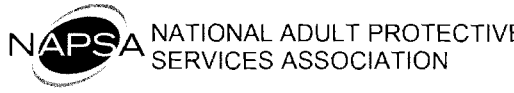
NIOSH established the AgFF program in 1990 in response to evidence that agricultural workers were suffering higher rates of injury and illness than other U.S. workers. The agriculture, forestry, and fishing, industry fatality rate is more than 8 times that of the all-industry average. Yearly, almost 18,000 workers in this sector are injured seriously enough to require time away from work.[1] Daily, an average of over 330 workers in this sector sustain injuries serious enough to require medical consultation, and nearly 2 workers die from an injury suffered at work.[2] Today, the initiative includes nine regional

[1] U.S. Bureau of Labor Statistics, U.S. Department of Labor. (2013). Table 2. numbers of nonfatal occupational injuries and illnesses by case type and ownership, selected industries, 2012. Retrieved February 12, 2014, from http://www.bls.gov/news.release/osh.t02.htm.
[2] National Safety Council. (2013). *Injury Facts®, 2013 Edition.*

centers and one national center to address children's farm safety. These centers conduct vital research leading to evidence-based standards that save lives. The AgFF Program is the only substantive federal effort to meet the obligation to ensure safe conditions for workers in this sector, and it is effective.

NIOSH supports education and research in occupational health through academic degree programs and research opportunities, primarily through 18 university-based ERCs located at leading universities around the country serving all 50 states. The mission of the ERCs is to reduce work-related injuries and illnesses in the U.S. by performing prevention research and by educating, through degree programs and continuing education, high-quality professionals who implement programs to improve occupational health and safety and minimize the dangers faced by workers across the country. The ERCs provide programs in a unique group of disciplines that benefit employers of all sizes and industries in every part of the country. Currently, the ERCs are responsible for supplying a good portion of the country's OSH graduates who will go on to fill professional roles. With an aging occupational safety and health workforce, and a shortage of qualified OSH professionals, ERCs are essential to educating the next generation of professionals.

Thank you again for the opportunity to submit testimony for the record.



US House of Representatives

Committee on Appropriations

Subcommittee on Labor, Health and Human Services,

Education, and Related Agencies

Hearing

Tuesday, March 25, 2014 10:00 AM

Written Testimony Submitted by the

National Adult Protective Services Association (NAPSA)

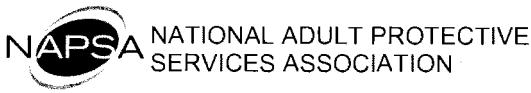
Kathleen M. Quinn, Executive Director

1,000 Thousand Victims A Day

The $25 million Elder Justice Act Funding Request for the HHS Administration on Community Living/Administration on Aging is urgently needed to adequately respond to victims as described below:

A state Adult Protective Services (APS) worker responded to a call about an 83-year-old woman living in her home under deplorable conditions, bedridden and suffering from dementia. Her 52-year-old son lived with her as her caregiver.

The woman appeared to have been neglected for an extended period of time and was confined to her bed, living in her own filth and infested with maggots. Her unemployed son had taken over $50,000 from his mother's bank accounts to buy a car and to gamble at casinos.



Also living in the home was a 48-year-old severely developmentally disabled daughter, also found living in filth and without adequate nutrition, as well as numerous malnourished dogs.

The APS worker took emergency measures to get medical evaluations and treatment for the mother and daughter, found an alternative living situation for the mother, worked with a local disabilities advocacy organization to place and assist the daughter, contacted animal control to take the dogs, had the house cleaned up. APS also referred the case to law enforcement, resulting in the son being arrested and charged with felony counts of criminal neglect and theft.[1]

The above is a description of an actual (and not atypical) elder and vulnerable abuse case that was handled by APS. Without APS, this older woman and her developmentally disabled adult daughter would have continued to suffer in the terrible conditions in which they were held captive, and their abuser son and brother would have never been held accountable for his cruelty and greed.

Research tells us that there are more elder abuse victims than victims of other types of abuse such as child abuse and domestic violence.[2] Research also estimates that ten percent of persons 60 and older are abused every year. This means that of the 10,000

[1]Quinn, K. & Benson. W. (2012). The States' Elder Abuse Services: A System Still in Search of Support. Generations. 36-3, 68.
[2] Sedlak, A.J., Mettenburg, J., Basena, M., Petta, I., McPherson, K., Greene, A., and Li, S. (2010). Fourth National Incidence Study of Child Abuse and Neglect (NIS–4): Report to Congress. Washington, DC: U.S. Department of Health and Human Services, Administration for Children and Families. http://www.acf.hhs.gov/programs/opre/abuse_neglect/natl_incid/index.html . ONE DEPARTMENT: OVERVIEW of ACTIVITIES ON VIOLENCE AGAINST WOMEN 2008-2009. DHHS Office of Women's Health http://www.womenshealth.gov/owh/pub/violence-against-women.cfm.

people a day who are turning 65, 1,000 of them are, have been or will likely be victims of elder abuse.[3]

Yet, older victims and adult victims with disabilities are the only victims of crime and abuse who receive no designated federal support for services. This is true even though federal support and attention to other types of abuse have been successful, resulting in, for example, reduced incidences of both child abuse and domestic violence homicides.[4]

Similar success can eventually be achieved if the Elder Justice Act is funded, starting with the FY 2015 modest request of $25 million to begin the development of a national infrastructure for Adult Protective Services.

Elder abuse causes great physical and emotional suffering, and results in greatly increased rates of hospitalization and premature death. *It is also extremely expensive, to the victims and their families, to financial institutions, and to taxpayers.* There are many older persons, for example, who must rely on Medicaid to pay for their long-term care after all their funds have been stolen from them.

APS Programs comprise the only victim services system in place in every community to go into the homes of these vulnerable adults to protect them from further abuse. Without federal support and leadership, APS Programs have evolved independently in every state,

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[3]Acierno, R., Hernandez, M. A., Amstadter, A. B., Resnick, H. S., Steve, K., Muzzy, W., & Kilpatrick, D. G. (2010). Prevalence and correlates of emotional, physical, sexual, neglectful, and financial abuse in the Congressional Record Feb. 10, 2003. http://thomas.loc.gov/cgi-bin/query/R?r108:FLD001:S02121United States: The National Elder Mistreatment Study. American Journal of Public Health, 100, 292-297.

[4] Dugan, L, Nagin, D & Rosenfeld, R. (2003) Do Domestic Violence Services Save Lives? NIJ Journal. 250 NIJ Journal 250 (November 2003): 20–25, NCJ 196548.

meaning that the training, standards, eligibility thresholds and resources available can differ dramatically from state to state and even from county to county. There are no national definitions, standards of practice, training and educational requirements, supervisor protocols, caseload standards, data systems or other basic prerequisites of well-developed social services programs.

It must be noted that APS in thirty-four states do receive funding through the federal Social Services Block Grant (SSBG) wherein each state decides how to allocate the federal block grant among its varied social services programs. In a recent NAPSA poll, 71% of the respondents in states which rely on SSBG funding for APS stated that loss of the funding would be either a very significant blow to, or would completely eliminate, their APS programs. Although it is sometimes stated that SSBG funds duplicate other federal funding, that is clearly not the case with APS, which receives no other federal monies. Social Services Block Grant funds are essential to maintaining APS services for vulnerable adult victims in every state, and the additional, APS-specific funding through the Elder Justice Act is critically needed to bring all APS programs up to minimum standards nationwide.

After over three decades of hearings and reports on the issue of elder abuse, we respectfully request that this Committee and this Congress heed the cries of these hidden victims of abuse, neglect and exploitation by supporting both Elder Justice Act and SSBG funding to insure that an adequate protective services system is available to victims in every community.

Thank you.

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
March 25, 2014

This statement includes the Fiscal Year 2015 (FY 2015) recommendations of the nation's Tribal Colleges and Universities (TCUs), in two areas of the Department of Education: Office of Postsecondary Education and Office of Vocational Education.

I. Higher Education Act Programs:

- **Strengthening Developing Institutions:** Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. The TCUs, which by any definition are truly developing institutions, funded under Title III-A Sec. 316 are providing quality higher education opportunities to some of the most rural/isolated, impoverished, and historically underserved areas of the country. The goal of HEA-Titles III/V 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-A 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 globally competitive workforce. Yet, in FY 2011 this critical program was cut by over 11 percent, by another four percent in FY 2012, and hit by sequestration – on the lowered baseline – in FY 2013. Although sequestration was not imposed in FY 2014, the TCUs have not recovered from the earlier cuts to this vitally important program. ***The TCUs urge the Subcommittee to restore the discretionary funding for HEA Title III-A, Sec. 316 to $30,000,000 in FY 2015.***
- **TRIO:** Retention and support services are vital to achieving the national goal of having the highest proportion of college graduates in the world by 2020. TRIO programs, such as Student Support

Services and Upward Bound, were created out of recognition that college access is not enough to ensure advancement and that multiple factors work to prevent the successful completion of postsecondary programs for many low-income and first-generation students and students with disabilities. Therefore, in addition to providing the maximum Pell Grant award level, it is critical that Congress also sustain student assistance programs, such as Student Support Services and Upward Bound so that low-income and minority students have the federal support necessary to allow them to remain enrolled in and ultimately complete their higher education degrees.

Pell Grants: The importance of Pell Grants to TCU students cannot be overstated. Approximately, 80 percent of TCU students receive Pell Grants, primarily because student income levels are so low and they 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. However, the U.S. Department of Education has changed its regulations to limit Pell eligibility from 18 to 12 full-time semesters, without any consideration of those already working towards a postsecondary degree. This change in policy has impeded some TCU students from completing a postsecondary degree, which is widely recognized as being critical for access to, and advancement in, today's highly technical workforce.

TCUs are open enrollment institutions. Recent placement tests administered at TCUs to first-time entering students indicated that 74 percent required remedial math, 54 percent required remedial reading, and 57 percent needed remedial writing. These results clearly illustrate just how serious this new Pell Grant eligibility limit is to the success of TCU students in completing a postsecondary degree. Students requiring remediation can use as much as a full year of eligibility enhancing their math, and or reading/writing skills,

thereby hampering their future postsecondary degree plans. A prior national goal was to provide access to quality higher education opportunities for all students regardless of economic means, at which TCUs have been extremely successful. While the new national goal intends to produce graduates with postsecondary degrees by 2020, this change in policy does not advance that objective. On the contrary, the new regulations will cause many low-income students to once again abandon their dream of a postsecondary degree, as they will simply not have the means to continue to pursue it. The goal of a well-trained technically savvy workforce will be greatly compromised. This new policy evokes the adage "*penny wise - pound foolish.*" *The TCUs urge the Subcommittee to continue to fund this essential program at the highest possible level, and to direct the Secretary of Education to implement a process to waive the very restrictive 12 semester Pell Grant eligibility for TCU students.*

II. Perkins Career and Technical Education Programs:

- **Tribally-Controlled Postsecondary Career and Technical Institutions:** Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions. ***AIHEC requests $8,200,000 to fund grants under Sec. 117 of the Perkins Act.***

- **Native American Career and Technical Education Program (NACTEP):** NACTEP (Sec. 116) reserves 1.25 percent of appropriated funding to support American Indian career and technical programs. *The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the continuation of career and technical education programs offered at TCUs that provide job training and certifications to remote reservation communities.*

III. 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 the absence of dedicated funding, TCUs must find a way, often using already insufficient institutional operating funds, to continue to provide adult basic 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 new GED exam, which was instituted in January 2014, has a much stronger focus on mathematics. As noted earlier, placement tests for TCU entering students reveal a tremendous need for math remediation. Additionally, the new GED test is fully computerized. While younger GED seekers may be well versed and comfortable with computer-based testing, older and poorer citizens may not be. These factors indicate a further and growing need for adult basic educational programs and GED preparation on Indian reservations. TCUs must have sufficient and stable funding to continue to provide these essential activities and to ensure their communities residents have the same chances to succeed as others throughout the country have. ***TCUs request that the Subcommittee direct that $8,000,000 of the funds appropriated annually for the Adult Education State Grants be made available to make competitive awards to TCUs to help meet the growing demand for adult basic education and remediation program services on their respective Reservations.***

FURTHER JUSTIFICATIONS FOR FY 2015 APPROPRIATIONS REQUESTS FOR TCUs

Tribal colleges and our students are already being disproportionately impacted by ongoing efforts to reduce the federal budget deficit and control federal spending. The FY 2011 Continuing Resolution eliminated all of the Department of Housing and Urban Development's Minority Serving Institutions (MSIs) community-based programs, including a critically needed TCU-HUD facilities program. TCUs were able to maximize leveraging potential, often securing even greater non-federal funding to construct and equip Head Start and

early childhood centers; student and community computer laboratories and public libraries; and student and faculty housing in rural and remote communities where few and sometimes none of these facilities existed. Important STEM programs, administered by the National Science Foundation and NASA were cut, and for the first time since the NSF program was established in FY 2001, no new TCU-STEM awards were made in FY 2011. While NSF-TCUP grants resumed in FY 2012, a year of grant opportunity was lost. TCUs Additionally, TCUs and their students suffer the realities of cuts to programs such as GEAR-UP, TRIO, SEOG, and as noted earlier, are seriously impacted by the new highly restrictive Pell Grant eligibility criteria more profoundly than mainstream institutions of higher education, which can realize economies of scale due to large endowments, alternative funding sources, including the ability to charge higher tuition rates and enroll more financially stable students, and access to affluent alumni. The loss of opportunity that cuts to DoEd, HUD, NSF, and NASA programs represent to TCUs, and to other MSIs, is magnified by cuts to workforce development programs within the Department of Labor, nursing and allied health professions tuition forgiveness and scholarship programs operated by the Department of Health and Human Services, and an important TCU-based nutrition education program planned by USDA. Combined, these cuts strike at the most economically disadvantaged and health-challenged Americans.

We respectfully request that the Members of the Subcommittee continue the federal investment in the nation's Tribal Colleges and Universities and full consideration of our FY 2015 appropriations needs and recommendations.

Testimony of Research!America to the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies Concerning FY15 Appropriations for the NIH, CDC and AHRQ
Submitted for the Record, March 25, 2014
Contact: Adam M. Katz, Policy and Advocacy Specialist, akatz@researchamerica.org

Research!America, the nation's largest public education and advocacy alliance committed to advancing medical research and development, appreciates your stewardship over such a critical subset of our nation's discretionary funding priorities. As the subcommittee begins the process of prioritizing FY15 funding, we urge you to consider the following thoughts on federal agencies entrusted with sustaining our nation's sophisticated public health infrastructure, partnering with the private sector to accelerate medical progress, and optimizing health care outcomes. For fiscal year 2015, we request that the National Institutes of Health receive at least $32 billion in federal funding, the Centers for Disease Control and Prevention receive funding that continues the growth in budget authority initiated in FY14, and the Agency for Healthcare Research and Quality receive at least $375 million in federal funding.

The National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ) play pivotal roles in combating disabling and deadly health conditions. Moreover, the funding, or lack of it, allocated to these agencies will bear on our nation's ability to compete in key export markets within the global economy, foster business development that grows and maintains jobs across the country, meet our solemn obligations to wounded warriors and support troops on the ground, combat deadly medical errors, and protect our nation against pandemics and emerging health threats. The stakes truly are that high.

NIH as a driver of innovation

In FY15, we urge you to provide at least $32 billion in NIH funding to drive us beyond the stagnation that squanders opportunities to advance science and strengthen our nation. Research funded by the NIH at universities, academic medical centers, independent research institutions and small businesses across the country lays the foundation for new product development by the private sector. Since much of the research NIH supports is at the non-commercial stages of the research pipeline, NIH funding does not compete with, but rather sets the stage for, critical private sector investment and development. These two complementary funding streams lead to business development, job growth and beneficial medical advances. Taxpayer-funded research through the NIH has helped our nation make remarkable progress against such insidious health threats as childhood cancer, HIV-AIDS and heart disease.

The secrets of diabetes, Alzheimer's, Parkinson's, myriad cancers and many other diseases can and will be unlocked by science. The question is not if, but when ... unless we dismiss the significance of such progress and continue to allow research resources to stagnate. And our nation's best weapon against spiraling health care costs is research. Ignoring growing health care costs is a ticket to disaster. Alzheimer's disease alone is projected to cost the federal government over $1 trillion during the next 20 years. Ultimately, we must prevent and cure disease in order to tackle the costs associated with it.

CDC as a first responder

In FY15, we urge you to provide a funding level that continues the growth in CDC budget authority that was initiated in FY14. The CDC engages in research that stems deadly and costly

pandemics, bolsters our nation's defenses against bioterrorism, and helps prevent the onset of debilitating and expensive diseases. The CDC is the nation's first responder to lethal viruses and infections, including life-threatening and costly drug-resistant infections that pose a particular threat to children and young adults, as well as investigating tragic phenomena like cancer clusters. Due to cuts in recent years, the CDC is functioning with one hand tied behind its back, even as health challenges like the obesity epidemic, autism epidemic and infectious disease outbreaks capture headlines and ruin lives. It is always more efficient and cost effective to be in front of an outbreak or biological attack than to take reactionary measures.

AHRQ translates medical innovation into the right care at the right time

In FY15, we urge you to provide at least $375 million in funding for AHRQ. Research supported by AHRQ identifies inefficiencies in health care delivery that inflate the cost of public and private insurance. AHRQ-supported research also combats medical errors and improves the quality of care to help reduce the length and intensity of disability and disease. It helps patients and physicians make informed treatment decisions that improve outcomes and reduce costly "false starts" in the provision of health care services.

Just one of many success stories is AHRQ's issuance of new standards of care and practices related to central line-associated bloodstream infections. The implementation of the guidelines resulted in a reduction of up to two-thirds of cases during early rollout studies. With an annual estimated 80,000 cases, up to 28,000 deaths and an average cost per patient of $45,000, this has the potential to save $2.3 billion annually in health care costs. Given the enormity of the challenge of inefficiency in health care delivery, AHRQ is severely underpowered.

The threat of sequestration's return

The Ryan-Murray Bipartisan Budget Act provided America with two years of partial relief from sequestration after across the board budget cuts dramatically impacted medical research in March 2013. Unfortunately, sequestration will go back into full effect in 2016 unless Congress takes action, and it will be in effect for two years longer than originally established under the 2011 Budget Control Act. The return of sequestration's budget cuts to discretionary spending, including that for NIH, CDC and AHRQ, poses potentially devastating setbacks to medical research. Short-changing medical research is not a solution to the federal deficit or debt. On the contrary, neglecting medical research undercuts strategies to fight chronic disease and the multipronged federal costs that arise from it, while squandering opportunities to increase private sector and federal revenues through new medical innovations.

Research!America appreciates the difficult task facing the subcommittee as it seeks to simultaneously confront the budget deficit, strengthen the U.S. and promote the well-being of Americans. There are few federal investments that confer as many benefits as medical research – new cures, new businesses, new jobs, new solutions to health care cost inflation, and new fuel to drive U.S. leadership in a global economy shaped by the ability of countries to continuously innovate. We firmly believe that investing in NIH, CDC and AHRQ is a means of advancing all three of these fundamental goals. Thank you for your leadership and consideration; we know that your task is extraordinarily difficult, and that our nation is fortunate to have such pragmatic, committed and gifted leaders at the helm.

VOR
Speaking out for people with intellectual & developmental disabilities

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TESTIMONY OF DAVID HART
CHAIR, VOR LEGISLATIVE COMMITTEE
VOR BOARD MEMBER

Written Testimony for the Record

Subcommittee on Labor, Health and Human Services, Education and Related Agencies, House Appropriations Committee

March 27, 2014

I. Introduction

VOR is a national organization that advocates for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). VOR calls on Congress to ***prohibit the use*** of U.S. Department of Health and Human Services' (HHS) appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from their HHS-licensed and funded Medicaid homes, in violation of federal law.

Deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics by some HHS-funded agencies (discussed below) resulting in the downsizing and closure of HHS-licensed homes are a cruel and absurd use of federal funding. These closures often lead to human tragedy. Medicaid-licensed facility homes, including Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) and other specialized nursing facilities, are uniquely suited to meet the residents' profound support, health care and behavioral needs. Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored.

II. Using HHS Funds to Eliminate HHS-Supported Homes: The Administration on Intellectual and Developmental Disabilities (AIDD) and its state-based Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Programs

It has been 14 years since Congress last reauthorized the DD Act. Authorizations for DD Act appropriations expired in 2007; however, Congress continues to fund these programs. DD Act programs, including Protection & Advocacy (P&A), DD Councils, and University Programs, operate in every state. AIDD, within HHS, administers the DD Act programs.

Independent oversight of federal AIDD and DD Act programs is nearly non-existent.[1] DD Act programs are using their public funds to achieve dangerous deinstitutionalization, evicting vulnerable people with I/DD from Medicaid-certified homes, disregarding individual choice and the legal right to appropriate services, as required by the Americans With Disabilities Act (ADA) (as interpreted by the *Olmstead* decision) and Medicaid law, both discussed below.

The DD Act programs' own authorizing statute supports residential choice and recognizes that individuals and their families are in the best position to make care decisions:

> "Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(2000); *see also*, H. Rep. 103-442 (March 21, 1994) ("[T]he goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions").

Yet, AIDD persists in its support for DD Act programs' deinstitutionalization activities and even proposed a recommendation to "[d]evelop and implement plans to close public and

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[1] See, VOR Federal Comments Urging Objective Performance - Not More Self-Reporting - of DD Act Programs (January 25, 2012) (vor.net/images/VORCommentDDActEvaluationJan2012.pdf)

private institutions," and "[k]eep people with disabilities out of congregate institutions," in collaboration with DOJ and The Arc (2011). Hundreds of families and others objected; the recommendation has not yet been finalized. Likewise, the national organizations for the three DD Act programs have referred to families who select HHS-licensed homes (ICFs/IID) as "clueless" and "unaware,"[2] a view not shared by the Supreme Court (*see, Heller v. Doe,* 509 U.S. 312, 329 (1993) (". . . close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process.")).

With AIDD directive, state-level DD Act program deinstitutionalization activities continue, exacting great harm on the very people Congress entrusted these HHS-entities to protect. Since 1996, more than fifteen (15) P&A class action lawsuits for closure (*not* relating to conditions of care) and other deinstitutionalization tactics have been pursued over the objection of residents and their families. The P&A class action lawsuits are a particularly egregious use of federal funds; **they equate HHS suing itself** because the targets of these HHS-funded lawsuits are HHS/Medicaid-licensed ICFs/IID.

AIDD and its state-based programs persist in their ideological devotion to community placement despite reports of 1,200 "unnatural and unknown" deaths in New York, a risk of mortality in community settings of up to 88% in California, more than 100 deaths in Connecticut, 53 deaths in Illinois, 114 deaths in the District of Columbia, plus many more reports of abuse, neglect and death across the majority of all states (*see e.g,* Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2014)).

[2] June 14, 2010 and July 30, 2007 letters to Congress referring to families as "unaware" and "clueless," respectively.

III. Using HHS Funds to Eliminate HHS-Supported Homes: National Council on Disability (NCD)

NCD is an HHS-funded, independent federal agency that advises the President, Congress, and other federal agencies on issues affecting people with disabilities.

On October 23, 2012, NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. NCD spent nearly $150,000 in federal funds to prepare and publish "Deinstitutionalization: Unfinished Business," calling on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes. NCD did not consult with the individuals who could be evicted from their homes, nor their families and legal guardians. Instead, NCD accuses these caring families and guardians of violating their family members' civil rights for choosing a care setting of four or more people. NCD has since received more than 350 letters from families opposing forced deinstitutionalization.

Like AAID, NCD cites the landmark Supreme Court decision of ***Olmstead v L.C.* (1999)** as justification for its position to close HHS homes. Like many organizations that support deinstitutionalization, AAID and NCD misread and misapply the *Olmstead* decision's requirements. The Supreme Court is clear in its holding that the ADA requires individual choice before community placement can be imposed and recognizes the need for specialized care:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead*, 119 S. Ct. 2176, 2187

(1999) (majority).

"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk ...'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution'[quoting VOR's *Amici Curiae* brief]." Id. at 2189 (plurality).

Likewise, **Medicaid law** and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. §441.302(d)(2); see also, 42 U.S.C. §1396n(c)(2)(C) and 42 C.F.R. §441.303.

NCD's support for deinstitutionalization is contrary to federal law and reckless. ICFs/IID have an array of services not often available elsewhere (*e.g.*, on-site medical care, dental care, other specialties, and involvement in their broader communities). As discussed above, tragedies are predictable when residents are separated from life-sustaining supports.

IV. Solution and Conclusion

HHS-funded agencies should not be allowed to advance an ideological agenda in support of evicting eligible people from HHS-licensed homes, contrary to the DD Act, Medicaid law, and the ADA/*Olmstead.* Such actions are a cruel and absurd use of federal funding that is exacting great harm on our nation's most vulnerable citizens, and contrary to societal values which respect individual and family decision-making.

Please support language to ***prohibit* the use of HHS appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from HHS-licensed and funded homes.** No federal agency should define "choice" so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population.

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National
Family Planning
& Reproductive Health Association

Testimony of Clare Coleman, President & CEO
National Family Planning & Reproductive Health Association

Submitted to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies

Re: Title X Family Planning Program
(Department of Health and Human Services/Office of Population Affairs)

March 25, 2014

Summary: Requesting $337 million in funding for Fiscal Year (FY) 2015 for the national family planning program (Title X of the Public Health Service Act).

My name is Clare Coleman; I'm the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a membership organization representing the nation's safety-net family planning providers—nurse practitioners, nurses, physicians, administrators and other key health care professionals. Many of NFPRHA's members receive federal funding from Medicaid and through Title X of the Federal Public Health Service Act, the only federally funded, dedicated, family planning program for the low income and uninsured. These critical components of the nation's public health safety net are essential resources for those providing access to high-quality services in communities across the country. As the Committees work on the Fiscal Year

(FY) 2015 appropriations bill, NFPRHA respectfully requests that you make a significant investment in Title X by including $337 million to restore the capacity of the program to serve those in need.

NFPRHA was disappointed to see the president's FY 2015 proposal only included $286.5 million for Title X. As more individuals gain access to health care coverage through the Affordable Care Act, the publicly funded family planning network will continue to play an essential role in our nation's service delivery framework, setting the standard for and providing high-quality care to all patients—the insured, uninsured, under-insured as well as patients seeking confidential services. If the Massachusetts health reform experience were to prove representative of what could be expected by nationwide health reform, there will be a strong increase in demand for services within the already-strained safety net. At present, six in ten women describe family planning centers as their usual source of medical care. According to a report by the Centers for Disease Control and Prevention (CDC), as health reform in Massachusetts expanded coverage for most people living in the state, Title X family planning health centers continued to have high volumes of patients, both insured and uninsured, and remained providers of choice for many.

The failure of states to expand Medicaid eligibility for all adults up to 138% of the federal poverty level (an income of $16,105 a year for an individual in 2014)—along with new barriers to coverage being sought by some expansion states, such as premiums and other cost-sharing requirements—compounds the demand being placed on the Title X safety net. Currently, 25 states have not expanded their Medicaid eligibility under the ACA. Twenty-one of these states have Medicaid eligibility equal to or less than 75% of FPL (an income of $8,753 a year); 14 have eligibility at or below 50% (an income of $5,835 a year). Five states have eligibility set at less than 25% of FPL—that means individuals making more than $2,918 are too "rich" for Medicaid.

Similar to other publicly funded health programs, Title X has unfortunately suffered budget cuts despite rising patient need. Between FY2010-FY2013, the Title X family planning program was cut $39.2 million (-12.3%). As a result, the total number of Title X users shrunk from 5.22 million users to 4.76 million during this time period, with no indication that patients went elsewhere for care. Congress made incremental progress in FY2014, funding Title X at $286.5 million, a restoration of $8.2 million over the FY2013 post-sequester level. As appropriators grapple with how best to distribute

limited federal resources, NFPRHA encourages the Committees continue to prioritize investments in programs, including Title X, that are proven to save critical taxpayer dollars. Every $1 invested in publicly funded family planning services saves $5.68 in Medicaid costs associated with unplanned births. Additionally, services provided in Title X-supported centers alone yielded $5.3 billion of the $10.5 billion in total savings for publicly funded family planning in 2010.

Lastly, Title X supports critical infrastructure and technology necessary for modern service delivery that are not reimbursable under Medicaid and commercial insurance. Resources for electronic health record implementation for safety-net providers—just as for others in the safety net—are necessary to help achieve the ACA goal of having a nationwide health information technology infrastructure and more coordinated models of care. Increased Title X funding is essential to help address the gap caused by the oversight in federal planning that led to most family planning health providers' ineligibility for the electronic health records (EHR) incentives available under the HITECH Act.

For these reasons, NFPRHA urges the Committees to make a significant investment in the nation's safety-net family planning health services and requests funding for Title X at $337 million in FY 2015.

Institution: National Technical Institute for the Deaf (NTID), Rochester Institute of Technology (RIT)
Submitted by: Dr. Gerard Buckley, President, NTID; Vice President and Dean, RIT
Email: gbuckley@ntid.rit.edu **Phone:** (585) 475-6317

Created by Congress in 1965, NTID is a "Special Institution" in the federal budget as well as one of nine colleges of RIT, in Rochester, N.Y. 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 deaf and hard-of-hearing individuals. On behalf of NTID, for FY 2015, I would like to request funding of $66,291,000, for our Operations budget. This is the same level of support that was provided in FY 2014. With our long history of successful stewardship of federal funds and outstanding educational record of service with people who are deaf and hard of hearing, NTID is a federal investment that *works*.

Enrollment:

NTID Enrollments: FY 2007 – FY 2014

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2014	1,195	42	18	1,255	147	30	177	1,432
2013	1,269	37	25	1,331	167	31	198	1,529
2012	1,281	42	31	1,354	160	33	193	1,547
2011	1,263	40	29	1,332	147	42	189	1,521
2010	1,237	38	32	1,307	138	29	167	1,474
2009	1,212	48	24	1,284	135	31	166	1,450
2008	1,103	51	31	1,185	130	28	158	1,343
2007	1,017	47	31	1,095	130	25	155	1,250

(In chart above, MSSE: Master of Science in Secondary Education of Deaf/Hard of Hearing; Grad RIT: other graduate programs at RIT.)

NTID students live, study and socialize with more than 16,000 hearing students on the RIT campus. Truly a national program, NTID has enrolled students from all 50 states. In Fall 2013 (FY 2014), we attracted 1,432 students, the sixth straight year of over 1,400 students. For FY 2015, NTID hopes to maintain this high enrollment, if our operational resources allow us to do so.

NTID Academic Model: NTID offers high quality, career-focused associate degree programs preparing students for well-paying technical careers. NTID also provides transfer associate degree programs to better serve the higher achieving segment of our student population seeking bachelor's and master's degrees. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including sign language interpreting, real-time speech-to-text captioning, and notetaking) 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. A cooperative education (co-op) component is an integral part of academic programming at NTID and prepares students for success in the job market. Almost 300 students last year participated in 10-week co-op experiences that augmented their academic studies, refined their social skills, and prepared them for the competitive working world.

Student Accomplishments: Over the past five years, an average of 91% of our graduates found jobs commensurate with their education level. Of our FY 2012 graduates, 93% were employed one year later, with 65% employed in business and industry, 24% in education/non-profits, and 11% in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In FY 2012, NTID, the Social Security Administration, and Cornell University examined earnings and federal program participation data for approximately 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The studies show that NTID graduates over their lifetimes are employed at a much higher rate, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in SSI and SSDI than students who withdrew from NTID.

Using SSA data, at age 50, 78% of NTID deaf and hard-of-hearing graduates with bachelor degrees report earnings and 73% of NTID deaf and hard-of-hearing graduates with associate degrees report earnings, compared to 58% of NTID deaf and hard-of-hearing students who withdrew from NTID. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, $58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and $41,000 is the median salary for NTID deaf and hard-of-hearing graduates with associate

degrees, compared to $34,000 for deaf and hard-of-hearing students who withdrew from NTID. Higher earnings, of course, yield higher tax revenues.

An NTID education also translates into reduced dependency on federal transfer programs, such as SSI and SSDI. At age 40, less than 2% of NTID deaf and hard-of-hearing associate and bachelor degree graduates participate in the SSI program compared to 8% of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18% of NTID deaf and hard-of-hearing bachelor degree graduates participate in the SSDI program and 28% of deaf and hard-of-hearing associate degree graduates participate in the SSDI program, compared to 35% of deaf and hard-of-hearing students who withdrew from NTID.

Budget Request Justification: NTID has worked hard to manage its resources carefully and responsibly. In order to address the challenges of three consecutive years of level federal funding, NTID significantly reduced equipment purchases and decreased its workforce by more than 70 staff – a 12% reduction. We also reduced our non-personnel expenditures by over 30% in such areas as building and equipment maintenance, instructional supplies, freelance interpreting, professional travel and student employment. NTID has also postponed requests for construction funding for critical and long overdue renovations to a 33-year old building currently housing three times the number of staff for which it was intended. In terms of non-federal revenues, from FY 2006 to FY 2014, student tuition and fees increased by 63% to offset the rising

costs of providing a state-of-the-art college education. Likewise, from FY 2006 to FY 2013, NTID raised almost $20 million in support from individuals and organizations. Our FY 15 request to continue FY 14 funding of $66,291,000 in Operations would allow us to maintain a balanced budget and avoid further harmful reductions. Without this funding, we would have to impose additional limitations in the areas of equipment purchasing, interpreting and captioning, scholarship support, building maintenance, and, most importantly, in personnel and enrollment. These are not the consequences a successful federal investment should face.

NTID has shown through hard data that our graduates have higher salaries, pay more taxes, and depend less on federal SSI/SSDI payments than their counterparts who do not attend NTID. Our placement rate is 91% over the past five years – even more remarkable given the state of the economy. Demand for an NTID education is higher than ever. Therefore, I ask that you please consider funding our FY 15 request of $66,291,000 for Operations. Likewise, we will continue to demonstrate to Congress and the American people that NTID is a proven economic investment in the future of young deaf and hard-of-hearing citizens.

SUBMITTED BY: TERESA K. WOODRUFF, PHD
PRESIDENT, THE ENDOCRINE SOCIETY

FY 2015 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY SUBMITTED BY THE ENDOCRINE SOCIETY FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

The Endocrine Society is pleased to submit the following testimony regarding Fiscal Year 2015 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 17,000 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 basic and clinical scientists who receive federal support from the NIH to fund endocrine-related research on topics ranging from diabetes, cancer, fertility, aging, obesity and bone disease. The Society's membership also includes clinicians who depend on new scientific advances to better treat and cure their patients' diseases. As a result of federal investment in endocrine research, individuals with diabetes have made dramatic improvements in managing their disease, and the obesity rate for children age 2 to 5 years old has dropped 43%[1,2]. The Endocrine Society recommends that the NIH receive at least $32 billion in FY 2015. This funding recommendation represents the minimum investment necessary to avoid further erosion of national research priorities and global preeminence, while allowing the NIH's budget to keep pace with biomedical inflation.

Sustained investment by the United States federal government in biomedical research has dramatically advanced the health and improved the lives of the American people. The United

[1] Casagrande et al., "The Prevalence of Meeting A1C, Blood Pressure, and LDL Goals Among People With Diabetes, 1988-2010." *Diabetes Care*, Aug 36;8 (2013) 2271-9.
[2] Sabrina Tavernise, "Obesity Rate for Young Children Plummets 43% in a Decade." *The New York Times*. Feb 25, 2014.

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States' NIH-supported scientists represent the vanguard of researchers making fundamental biological discoveries and developing applied therapies that advance our understanding of, and ability to treat human disease. In the past year NIH funded scientists have made fundamental insights into how mild traumatic brain injury causes brain damage; identified potential drug targets for Parkinson's disease; and identified a safe and protective candidate malaria vaccine.[3] In the field of endocrinology, NIH-funded researchers have made remarkable contributions in areas of critical national interest, for example:

- Endocrinologists have made insightful discoveries describing newly understood contributors to body weight and obesity[4]. Obesity is a growing national concern, with related medical costs in the United States as high as $190 billion in 2005 alone[5].
- Endocrinologists have discovered that higher vitamin D levels are associated with increased mobility and physical function in older individuals. As the population of the United States increasingly lives longer, this research has the potential to dramatically improve the quality of life for Americans[6].
- Endocrinologists are also at the leading edge of research on testosterone therapy and maintaining appropriate levels of sex hormones. For instance, endocrinologists are investigating links between testosterone levels and heart disease in men[7].

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[3] "2013 Research Highlights". December 23, 2013. http://www.nih.gov/researchmatters/january2014/researchmatters2013recap.htm Accessed March 23, 2013.
[4] Mathur et al., "Methane and hydrogen positivity on breath test is associated with greater body mass index and body fat." *J Clin Endocrinol Metab.* 98;4 (2013) 698-702.
[5] Cawley and Meyerhoefer. "The medical care costs of obesity: an instrumental variables approach." *J Health Econ.* 31;(2012) 219-30.
[6] Wohl et al., "Vitamin D status is associated with functional limitations and functional decline in older individuals." *J Clin Endocrinol Metab.* 98;9 (2013) 1483-90.
[7] Ruige et al., "Beneficial and Adverse Effects of Testosterone on the Cardiovascular System in Men." *J Clin Endocrinol Metab.* 98;11 (2013) 4300-10.

These discoveries represent but a fraction of the contributions made by endocrinologists and other NIH funded scientists in the past year. The foundation for these research products are the NIH research grants that support the basic and clinical research done by scientists. Since 2004, the number of NIH research grants to scientists in the United States has been declining. Consequently, the likelihood of a scientist with a highly-regarded grant application successfully being awarded a grant has dropped from 31.5% in 2000 to an historic low of 16.8% in 2013[8]. This means that experienced scientists are increasingly spending time writing grant applications instead of applying their expertise to productive research. Additionally, younger scientists struggle to find a job in the United States that makes use of the unique skills generated during graduate training.

The lack of sustained government support compounded by austerity measures such as sequestration has created an environment that is leading to a "brain drain" as brilliant scientists pursue other careers or leave the United States to develop impactful research products elsewhere. In 2013, the number of NIH supported scientists declined significantly, with nearly 1,000 NIH scientists dropping out of the workforce[9]. NIH scientists run labs that support high-quality jobs and education while generating breakthrough innovations. In 2011, the NIH directly or indirectly supported over 432,000 jobs across the country[10]. As a result of sequestration, states such as Georgia and Connecticut lost $62 million and $32 million respectively[11].

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[8] Salley Rockey, "FY2013 By The Numbers: Research Applications, Funding, and Awards," *Rock Talk*, January 10, 2014. http://nexus.od.nih.gov/all/2014/01/10/fy2013-by-the-numbers/ Accessed March 20, 2014.
[9] Jeremy Berg "The impact of the sequester: 1,000 fewer funded investigators." *ASBMB Today*. March (2014). https://www.asbmb.org/asbmbtoday/201403/PresidentsMessage/ Accessed March 20, 2014.
[10] Everett Ehrlich "Engine Stalled: Sequestration's Impact on NIH and the Biomedical Research Enterprise." *United for Medical Research*. (2012).
[11] "NIH State Information Factsheets." http://www.faseb.org/Policy-and-Government-Affairs/Advocacy-on-Capitol-Hill/Advocacy-Resources-for-Scientists/NIH-State-Information-Factsheets.aspx. *Federation of American Societies for Experimental Biology*. Accessed March 19, 2014.

We may never be able to quantify the opportunities we have missed to improve the health and economic status of the United States due to persistent underinvestment in research. We do know however, that when "laboratories lose financing, they lose people, ideas, innovations and patient treatments[12]." Based on the personal stories of researchers who have been forced to curtail research programs, we know that research programs to understand how genetics can influence heart disease, develop therapeutic treatments for Parkinson's disease, and evaluate the effect of metal contaminants on reproductive health; among many others, are delayed or terminated[13].

As the world's largest source of funding for medical research, the NIH is vitally important to the United States' global preeminence in research. However, this global preeminence is being tested due to flat funding that has reduced the inflation-adjusted budget of the NIH to a level that is nearly 22% below the NIH budget in FY 2003[14]. As a consequence of this underinvestment, the United States' global share of pharmaceutical industry output has declined, our global share of biopharmaceutical patents has declined, and our trade balance in pharmaceutical products is worsening[15]. While the Bipartisan Budget Act of 2013 and omnibus appropriations bill have provided some much needed additional resources, overall levels of funding remain well below the $32 billion required for adequate, sustainable growth in biomedical research.

We live during an age of tremendous scientific opportunity that can only be realized through federal funding of biomedical research. Researchers are only beginning to harness the power of big data to solve complicated problems. Innovative new experiments and clinical research hold

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[12] Teresa K. Woodruff "Budget Woes and Research." *The New York Times.* September 10, 2013.

[13] Sequester Profiles: How Vast Budget Cuts to NIH are Plaguing U.S. Research Labs. *United for Medical Research.* http://www.unitedformedicalresearch.com/advocacy_reports/sequestration-profiles/ Accessed March 20, 2014.

[14] "Budget Cuts in 2013 Reduced Biomedical Research" *Federation of American Societies for Experimental Biology.* http://www.faseb.org/pdfviewer.aspx?loadthis=http%3A%2F%2Fwww.faseb.org%2FPortals%2F2%2FPDFs%2Fopa%2F2014%2F1.21.14%2520NIH%2520Funding%2520Cuts%25202-pager.pdf Accessed March 19, 2014.

[15] Atkinson et al., "Leadership in Decline, Assessing U.S. International Competitiveness in Biomedical Research." *The Information Technology and Innovation Foundation and United for Medical Research.* May 2012.

promise to solve some of the United States' greatest medical challenges and discover new ways to improve our quality of life. Government support is critical to these opportunities, and we encourage the Appropriations Committee to actively support promising and innovative research.

As the Appropriations Committee considers funding for the NIH, the Endocrine Society also asks the Committee to encourage the NIH to look at ways to increase data reporting to address gaps in gender and sex differences in research. Sex differences need to be acknowledged as a critical biological variable[16]. In addition to including more women in clinical research, the Endocrine Society believes sex differences should be included as part of the design of all basic biological studies and clinical research. If the NIH required researchers to consider sex differences in grant applications when appropriate, and incorporate data on sex as a biological variable in animal and human studies, more appropriate conclusions could be drawn from basic research, and clinical research would provide more representative data on safety and efficacy of drugs[17].

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the federal government. Flat funding in recent years, combined with the impact of sequestration, threaten the nation's scientific enterprise and make adequate FY 2015 appropriations for the NIH increasingly important. The Society strongly supports increased federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address scientific opportunities and maintain the country's status as the preeminent research engine. The Endocrine Society therefore asks that the NIH receive at least $32 billion in FY 2015.

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[16] Woodruff et al., "'Leaning in' to Support Sex Differences in Basic Science and Clinical Research." *Endocrinology*. 155;4 (2014) 1181-3

[17] Kim et al., "Sex Bias in Trials and Treatment Must End." *Nature*. 465;7299 (2010) 688-9.

Written Statement of Carol Ann Mason, President, Society for Neuroscience
(202) 962-4000 - Email: advocacy@sfn.org
Subcommittee on Labor, Health, and Human Services, Education, and Related Agencies
Appropriations Committee, United States House of Representatives
In support of FY 2015 Appropriations for the NIH
March 28, 2014

Mr. Chairman and members of the Subcommittee, my name is Carol Ann Mason, Ph.D. I am a professor of pathology and cell biology, neuroscience, and ophthalmic science at Columbia University. I study the development of visual pathways in mammalian brains, with a focus on how neurons in the eye are encoded to project to the correct side of the brain, setting up the circuit for binocular vision. This statement is in support of increased funding for NIH for FY 2015. I submit this testimony in my capacity as president of the Society for Neuroscience (SfN). On behalf of the nearly 40,000 members of SfN, thank you for your past support of neuroscience research at NIH.

The Society stands with others in the research community in requesting at least $32 billion for NIH for FY 2015. Sequestration is taking an enormous toll on biomedical research, coming on top of recent years when funding has failed to keep pace with the cost of research – let alone the scientific opportunities that are available. SfN urges Congress to reverse the current course and find ways to invest more in biomedical research. Let's work to put biomedical research on a trajectory of sustained growth that recognizes its promise and opportunity as a tool for economic growth and, more importantly, for advancing the health of Americans.

Major research advances on brain development, imaging, genomics, circuits, computational neuroscience, neural engineering, and many other disciplines are leading to new tools, new knowledge, and greater understanding that were unimaginable even a few years ago. Sustained investment to fuel and speed these discoveries is essential to American health and economic well-being for many reasons.

First, major investment in basic and translational neuroscience is not only fueling an enduring and vital scientific endeavor, it is the essential foundation for understanding and treating diseases that strike nearly 1 billion people worldwide. All told, there are more than 1,000 debilitating neurological and psychiatric diseases that strike over 100 million Americans each year, producing inestimable hardship for millions of America families and costing the U.S. at least $760 billion a year, with expenses in the trillions looming for conditions such as Alzheimer's disease. Advances made possible by publicly-funded basic research will help better understand and treat traumatic brain injury, Alzheimer's, Parkinson's disease, Down syndrome, schizophrenia, epilepsy, and post-traumatic stress disorder, to name just a few. With so much promising research, now, more than ever, it is time to fan the flames of research in order to ensure lifesaving breakthroughs continue.

Without robust, sustained investment, America's status as the preeminent leader in biomedical research is at risk. Other countries are investing heavily in biomedical research to take advantage of new possibilities. Even with the growing philanthropic support, private sector cannot be expected to close the gap. The lag time between discovery and profitability means that the pharmaceutical, biotechnology, and medical device industries need federally-funded basic (also known as fundamental) research to develop products and treatments. The foundation that basic research provides is at risk if federally-funded research declines.

The Brain Research through Application of Innovative Neurotechnologies (BRAIN) Initiative – announced by the President last April - will enable NIH and other federal agencies to develop tools and plans that will help accelerate fundamental discoveries and improve the health and quality of life for millions of Americans. An eminent group of neuroscientists with diverse research interests is helping to formulate a scientifically-driven direction for the initiative, and

SfN thanks public leaders for their interest and early support for a truly transformative scientific grand challenge that would need major financial emphasis in future years.

The overarching goal of the BRAIN Initiative is to map the circuits of the brain and the activity within those circuits to understand our unique cognitive and behavioral capabilities. The Initiative has a strong focus on developing technologies which has the potential to benefit all of neuroscience and even non-neuroscience research. But BRAIN – as with all the neuroscience research that takes place with federal support – can only be successful if it is part of a broad neuroscience commitment across Congress and the Administration. Such an investment will also help ensure the U.S. remains a global leader, as other nations and regions are now rapidly ramping up their investments in neuroscience research.

A prime example of the importance of funding research at levels from the most basic to translational is the current focus on understanding brain circuits. Circuits in the brain underlie every thought, emotion, and action wc take. Current knowledge about the intricate patterns connecting brain cells is extremely limited. Identifying these patterns is essential to understand healthy brain function and dysfunction in injury or disease. Elucidating brain circuit structure and function is an enormously challenging endeavor; the brain consists of billions of cells, and each cell contacts thousands of others. These cells communicate with precisely-timed signals, which then activate a multitude of biochemical pathways that influence every process in the cell. Scientists are beginning to map the functions of brain circuits with previously unheard-of specificity using cutting-edge technologies, and learning how these circuits produce behaviors.

Optogenetics is a technique which uses light to activate specific populations of neurons with millisecond precision. Flashes of light are used to activate neurons that have been genetically modified to contain a light-sensing protein. This precise control over specific

populations of neurons at specific times was impossible until a confluence of basic research in marine biology, genetic engineering, cellular biology, and fiber optic technology facilitated its development; together these developments created an approach that enables the proteins to be used as "on switches" for cells. Introduced a decade ago, optogenetics is now used by hundreds of labs; it is one of the many neurotechnologies that today is transforming the field's ability to understand brain function, and is being used to study brain circuits in both normal function and disease, including Parkinson's disease, as described below. The development of this technology also perfectly demonstrates the often serendipitous nature of scientific discovery and the need to fund both research on all levels, from basic to translational to clinical.

My own area of research is the development of the circuits underlying vision. For binocular vision to function, the brain must receive information from both eyes. Nerve fibers from each retina grow to the 'optic chiasm,' at the midline of the bottom of the brain. Here, nerve fibers from each eye cross to the other side of the brain. Other axons, however, are repelled at the midline and project to the same side of the brain. These connections underlie binocular vision which enables animals, including humans, to calculate how far objects lie in the distance. One area of my research focuses on this question and the molecular mechanisms that prompt some growing nerve fibers to "stop in their tracks" and reroute to the same side. These two groups of cells in the eye, each taking different routes, are endowed with distinct genes that direct their time of birth and their growth to the regions where they make their synaptic connections. Understanding their genetic "signatures" and growth helps us to learn how to encourage stem cells to be integrated into the diseased eye and injured nerve fibers to regrow in the correct circuits. We also investigate how the retinal pigment epithelium (RPE) surrounding the eye, directs retinal development. Perturbations in the RPE occur in albinism and in juvenile

forms of macular degeneration, the latter leading to blindness, and our gene identification efforts are important for gene therapy at early stages of the disease. Moreover, understanding how tracts are laid down is essential for unraveling the basis of defects in fiber pathways and synapse formation in neurodevelopmental disorders such as autism. This research is made possible with support primarily from NIH, especially the National Eye Institute and with a team of innovative and collaborative scientists and trainees in my lab and in our community, and provides a foundation for future discovery and new understanding about diseases of the eye and other neurodevelopmental conditions.

As the subcommittee considers this year's funding levels, please consider that significant advancements in the biomedical sciences often come from young investigators. As a director of the PhD training program of a leading neuroscience department, I see firsthand that the current funding environment is taking a toll on the energy and resilience of these young people and their career choice. America's scientific enterprise—and its global leadership—has been built over generations. Without sustained, consistent investment, we will quickly lose that leadership. Dramatic swings in funding have stifling and irreversible impacts on progress; a closed laboratory can't simply open again when funding is restored. The culture of entrepreneurship and curiosity-driven research could be hindered for decades.

We live at a time of extraordinary opportunity in neuroscience. A myriad of questions once impossible to consider are now within reach because of new technologies, an ever-expanding knowledge base, and a willingness to embrace many disciplines. To take advantage of the opportunities in neuroscience we need an NIH appropriation that allows for sustained, reliable growth. That, in turn, will lead to improved health for the American public and will help maintain American leadership in science worldwide. Thank you for this opportunity to testify.

RAILROAD RETIREMENT BOARD
OFFICE OF INSPECTOR GENERAL
FISCAL YEAR 2015 BUDGET REQUEST

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES OF THE COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES

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STATEMENT FOR THE RECORD

March 28, 2014

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

The President's proposed budget for Fiscal Year (FY) 2015 would provide $8,750,000 to the Office of Inspector General (OIG) to ensure the continuation of the OIG's independent oversight of the Railroad Retirement Board (RRB). During FY 2015, 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 five domicile investigative offices located in Virginia, Texas, California, Florida, and New York. 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

The mission of the Office of Audit (OA) is 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 2015, 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 and Railroad Unemployment Insurance Act

Benefit Program Operations; Railroad Medicare Program Operations; and Security, Privacy, and Information Management. OA must also 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, evaluation of information security pursuant to the Federal Information Security Management Act (FISMA), and an audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010.

During FY 2015, OA will complete the audit of the RRB's FY 2014 financial statements and begin its audit of the agency's FY 2015 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 in FY 2006. 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

The Office of Investigations (OI) focuses its efforts on identifying, investigating, and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB disability, unemployment, sickness, and retirement/survivor benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also conducts investigations involving fraudulent claims submitted to the Railroad Medicare Program. These investigative efforts can result in criminal convictions, administrative sanctions, civil penalties, and the recovery of program benefit funds.

OI Investigative Results for FY 2013

Civil Judgments	Indictments/Informations	Convictions	Recoveries/Receivables
37	47	81	$414,254,000 1/

OI anticipates an ongoing caseload of about 400 investigations in FY 2015. During FY 2013, OI opened 156 new cases and closed 238. At present, OI has cases open in 48 states, the District of Columbia, and Canada with estimated fraud losses of nearly $217 million. Disability fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

1/ This total includes the results of joint investigations with other agencies.

Of particular significance is an ongoing disability fraud investigation in New York. To date, 32 individuals have been indicted; 28 of these have pleaded guilty and five more were convicted in Federal court. In addition, 44 former railroad employees avoided prosecution by admitting their role in the fraud and agreeing to the termination of their benefits. OI agents will likely have to spend a substantial amount of time traveling to New York for continuing investigations and trial preparation in FY 2015.

During FY 2015, 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 2015, 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.

RAILROAD RETIREMENT BOARD
FISCAL YEAR 2015 BUDGET REQUEST
Statement for the Record, March 28, 2014

HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

Michael S. Schwartz, Chairman of the Board
Walter A. Barrows, Labor Member of the Board
Jerome F. Kever, 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 2015 budget request of $112,150,000 for our retirement, unemployment and other programs.

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. The RRB has also administered special economic recovery payments and extended unemployment benefits under the American Recovery and Reinvestment Act of 2009 (P.L. 111-5) and extended unemployment benefits under the Worker, Homeownership, and Business Assistance Act of 2009 (P.L. 111-92). More recently, we have administered extended unemployment benefits under the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (P.L. 111-312), the Temporary Payroll Tax Cut Continuation Act of 2011 (P.L. 112-78), the Middle Class Tax Relief and Job Creation Act of 2012 (P.L. 112-96) and the American Taxpayer Relief Act of 2012 (P.L. 112-240).

During fiscal year 2013, the RRB paid $11.7 billion, net of recoveries, in retirement/ survivor benefits to about 568,000 beneficiaries. We also paid $84.5 million in net unemployment/sickness insurance benefits to more than 26,000 claimants. Temporary extended unemployment benefits paid were $6.8 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to $1.4 billion to about 113,000 beneficiaries.

PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The President's proposed budget would provide $112,150,000 for agency operations, which would enable us to maintain a staffing level of 860 full-time equivalent staff years (FTEs) in 2015. The proposed budget would also provide $2,500,000 for information technology (IT) investments for the conversion of a legacy Program Accounts Receivable (PAR) system to a modern accounts receivable module within our cloud-based core financial system that was implemented October 1, 2013.

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. About 63 percent of our employees have 20 or more years of service, and over 28 percent of our current workforce will be eligible for retirement by fiscal year 2015. As we continue to modernize our information technology infrastructure to automate and convert manual workloads, our agency will also improve training delivery and reporting within our workforce. We plan to acquire and implement a Learning Management System that will provide a comprehensive functionality for training administration, documentation, tracking, reporting and delivery of e-learning education and training programs. This will allow the agency to improve all aspects involved in the learning process to meet our

human capital needs as we experience a high rate of change in personnel. Furthermore, we will complement this initiative by implementing an executive training program to prepare and mentor future agency leaders that are ready to replace a significant number of senior leaders within the agency that are eligible to retire.

In connection with these workforce planning efforts, the President's budget request 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. Also, our budget request includes a legislative proposal to clarify the authority of the Railroad Retirement Board to retain in the competitive civil service attorneys hired prior to a change in OPM policy in 2013.

INFORMATION TECHNOLOGY IMPROVEMENTS

We are actively pursuing further automation and modernization of the RRB's various processing systems to support the agency's mission to administer benefit programs for railroad workers and their families. In fiscal year 2015, funding is included for contractor support to complete the full design of the Financial Management Integrated System (FMIS) by migrating a benefit payment feeder system named Program Accounts Receivable (PAR) to FMIS. FMIS migration from an obsolete financial system was started Oct 1, 2012 and completed Oct 1, 2013. Due to reduction in funds of the FMIS program during the sequestered fiscal year, PAR migration into FMIS was delayed. Once completed, the PAR migration to FMIS will enhance the processing of debt transactions for improper benefit payments in an integrated financial

system hosted in a cloud environment. We expect PAR migration to FMIS to reduce staffing requirements and improve efficiency of the improper payment process.

OTHER REQUESTED FUNDING

The President's proposed budget includes $34 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, $680,000, 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, 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 coordinates its financial needs with the National Railroad Retirement Investment Trust (Trust), the Trust 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. Through December 2013, the Trust had transferred approximately $15.4 billion to the Railroad Retirement Board for payment of railroad retirement benefits. The net asset value of Trust-managed assets on September 30, 2013, was approximately $25.0 billion, an increase of almost $1.4 billion from the previous year.

In June 2012, we released the 25th Actuarial Valuation of the railroad retirement system required by Sections 15(g) of the Railroad Retirement Act of 1974. That report also met the requirements of Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The report addressed the 75-year period 2011-2085,

including projections of the status of the retirement trust funds under three employment assumptions. It concluded that barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system would experience no cash flow problems for the next 23 years. Even under the most pessimistic assumption, the cash flow problems would not occur until the year 2035. The report did not recommend any change in the rate of tax imposed by current law on employers and employees.

The RRB's latest annual report required by Section 502 of the Railroad Retirement Solvency Act of 1983 was released in June 2013. The overall conclusion was that barring a sudden unanticipated, large decrease in railroad employment or substantial investment losses, the railroad system will experience no cash flow problems during the next 25 years.

Railroad Unemployment Insurance Account – The RRB's latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2013. The report indicated that even as maximum daily benefit rates will rise approximately 42 percent (from $66 to $94) from 2012 to 2023, experience-based contribution rates are expected to keep the unemployment insurance system solvent, except for small, short-term cash-flow problems in 2015 and 2016 under the most pessimistic assumption. However, projections show quick repayment of any loans by the end of each fiscal year.

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.

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Testimony of the Parkinson's Action Network
Fiscal Year 2015 Appropriations
at the U.S. 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

March 25, 2014

Dear Chairman Kingston and Ranking Member DeLauro,

The Parkinson's Action Network (PAN) appreciates the opportunity to comment on the Fiscal Year (FY) 2015 appropriations for the U.S. Department of Health and Human Services. Our comments will focus on the importance of federal investment in biomedical research at the National Institutes of Health (NIH) and the National Institute of Neurological Disorders and Stroke (NINDS), which recently adopted a series of priority research recommendations for Parkinson's disease. PAN supports at least $32 billion in funding for the NIH and an increase for NINDS to support the research recommendations set forth by the NINDS planning strategy to bring us closer to better treatments and a cure for Parkinson's disease.

PAN is the unified voice of the Parkinson's community advocating for better treatments and a cure. In partnership with other Parkinson's organizations and our powerful grassroots network, we educate the public and government leaders on better policies for research and improved quality of life for the estimated 500,000 to 1.5 million Americans living with Parkinson's, for whom there is no treatment available that slows, reverses, or prevents progression.

As the second most common neurodegenerative condition after Alzheimer's disease, Parkinson's disease is projected to grow substantially over the next few decades as the size of the elderly population grows and will have a direct impact on the health care system and economy. A study published in *Movement Disorders* estimated that the economic burden of Parkinson's disease is at least $14.4 billion a year in the United States, and the prevalence of Parkinson's will more than double by the year 2040.[1] In addition, the study calculated an additional $6.3 billion in indirect costs such as missed work or loss of a job for the patient or family member who is helping with care, long-distance travel to see a neurologist or movement

[1] "The Current and Projected Economic Burden of Parkinson's Disease in the United States," *Movement Disorders, Vol. 28, No. 3, 2013.*

disorder specialist, as well as costs for home modifications, adult day care, and personal care aides.

A second study also published in *Movement Disorders* projected that if Parkinson's progression were slowed by 50 percent, there would be a 35 percent reduction in excess costs, representing a dramatic reduction in cost of care spread over a longer expected survival.[2] Both studies highlight the enormous economic implications of this devastating disease, and make it abundantly clear that increased research funding is a wise investment on the front end to help significantly lower or eliminate costs on the back end.

NIH has the unique role of being at the forefront of medical discovery in the United States. NIH supports research in all fifty states, with more than 80 percent of the funding going to universities, research institutions, and small businesses, which create thousands of jobs and grow local economies. In 2012, this amounted to over 402,000 jobs nationwide and $57.8 billion in economic activity. Perhaps even more important than their economic contributions is the practical impact NIH grants have in identifying and developing a better understanding of and treatments for countless complex diseases and disorders.

There is currently a concerted effort at NIH to better target areas of unmet medical need, including Parkinson's research. In January 2014, NINDS approved a list of 31 priority research recommendations specific to Parkinson's that highlight areas in which NINDS and the broader field should direct its resources to achieve the greatest impact in addressing treatments and the underlying causes of the disease. These recommendations were the result of an intensive planning process that brought together clinicians, researchers, and the patient community to determine the areas of greatest need to reframe how we approach the disease. We applaud NINDS for their leadership in this effort, which represents an unparalleled opportunity to coordinate critical initiatives to help unlock the mysteries of Parkinson's - but its success is dependent upon strengthening funding at NIH and NINDS to ensure that sufficient capacity and resources are available.

Unfortunately, due to ongoing fiscal constraints, including sequestration, the NIH research budget has not kept pace with inflation or the growing needs of an aging population and the overall public health. Sequestration alone cut over $1.55 billion from NIH in FY 2013, which is roughly equivalent to the entire budget for NINDS. NIH, the largest funder of Parkinson's research in the world, was also forced to reduce its Parkinson's-related research from a high of $154 million in FY 2012 to $135 million in FY 2013, a 12 percent decrease. Across the country, many institutions have felt the burden of these cuts, receiving smaller grants or no grants at all. As NIH continues to find high-priority areas to fund in order to advance Parkinson's research, we should be increasing support and not applying cuts that could possibly delay years of progress toward a cure for Parkinson's and other diseases.

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[2] "An Economic Model of Parkinson's Disease: Implications for Slowing Progression in the United States," *Movement Disorders, Vol. 28, No. 3, 2013.*

Despite some greater certainty in the current appropriations cycle because of the budget agreement passed in December 2013, there is still grave concern over the implications for medical research long-term. Dr. Francis Collins, director of NIH, has even noted that "without sustained investment, many high-priority efforts would move at a substantially slower pace, and years of effectively flat funding for biomedical research have left scientists facing the lowest chances in history of having their research funded by NIH."[3] Because of this trend, there is also the fear that the next generation of scientists will leave the United States or be reluctant to enter the field of neurological research at all because of the uncertainty in financial support they see and feel here at home. Innovation and new possibilities for medical research are at our fingertips, and we must be sure that we have the resources in place to fully recognize and cultivate their potential.

We recognize that due to spending caps put into place by the 2013 budget agreement, the President's FY 2015 budget proposal only requests a modest increase for NIH and many other important programs. But, we also understand that the final decision on how these funds should be allocated within those caps is the responsibility of Congress – and we look to you for your leadership and support. PAN urges the Subcommittee to prioritize biomedical research funding by supporting at least $32 billion for the NIH overall and increasing funding for NINDS to advance critical priorities designed to fundamentally change our understanding of Parkinson's disease. We look forward to working with the Subcommittee as the FY 2015 appropriations process moves forward.

[3] "Investing in the Nation's Health," Dr. Francis Collins. *The Washington Post*. Opinions. December 24, 2013.

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STATEMENT TO THE

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION

AND RELATED AGENCIES

APPROPRIATIONS SUBCOMMITTEE

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SENIOR VICE PRESIDENT, GOVERNMENT RELATIONS

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Mr. Chairman and Members of the Subcommittee:

Thank you for the opportunity to speak on behalf of Easter Seals about our federal funding priorities for fiscal year (FY) 2015. Easter Seals is a national nonprofit organization that provides essential community-based services to individuals with disabilities, older adults, veterans and other underserved populations to help them live, learn, work and contribute to their communities. Easter Seals' top priorities are in the people we serve like Arlena, Ben, Elijah and Donald whose lives have been impacted or could be through federal investments made by this subcommittee. Easter Seals respectfully asks that you consider these stories and the critical programs these individuals as the subcommittee develops its FY 2015 bill. Specifically Easter Seals requests that the Senior Community Service Employment Program be funded at $434,371,000 for FY 2015, the Homeless Veterans' Reintegration Program be funded at $50,000,000 for FY 2015, the Early Intervention Grants for Infants and Families be funded at $458,498,000 for FY 2015, and the Department of Education Transition Model System be funded at $15,000,000 for 2015.

MEET ARLENA: Arlena is an older worker who is contributing to her New Jersey community as a full-time security supervisor at a major airport. Her success may have seemed out-of-reach less than two years earlier when the 55-year-old single mother faced dual challenges. Arlena had lost her temporary job and was out of work for about a year when Hurricane Sandy hit and further complicated matters. She lost her home and all of her belonging in the 2012 storm, which left her homeless. She was forced to move in with her daughter's family. Eventually her daughter moved and gave her the apartment. However, with no job she fell behind in her rent and utilities. She turned to Easter Seals for help after hearing about the Senior Community Service Employment Program (SCSEP) through a friend. The Department of Labor program supports employment of older workers by providing part-time, paid community service positions and work-based training for unemployed, low-income individuals, age 55 and older. Through the federal program, Easter Seals connected Arlena to supportive services to help her maintain an apartment, boosted her computer skills and matched her with on-the-job training at three different community locations. After 9 months in the program, she applied for

and secured an entry level security position. Based on her previous work history, Arlena was promoted to a supervisory position. SCSEP helped to provide Arlena the tools and opportunities she needed to prove she could bounce back from adversity and contribute again to her community. Easter Seals asks that the subcommittee supports a FY 2015 funding level of $434,371,000 for SCSEP, the same level the program received in FY 2014.

MEET BEN: Ben was almost among the one million children under age 5 with disabilities who go undiagnosed every year. Ben's mom felt uneasy about her son's language progress when he was 18 months. But her doctor attributed the speech delays to being raised in a bilingual household. After the birth of Ben's brother six months later, Ben's mom became more concerned about Ben's development, this time related to his behavior. "I knew that Ben needed help." So she reached out to her state's Birth to Three program – which is funded through Part C of the Individuals with Disabilities Education Act – and soon Ben was receiving needed speech and occupational services from Easter Seals and was diagnosed with a form of autism called PDD-NOS. Within six months of receiving early invention services, Ben was able to communicate in sentences. Now four years old, he continues to work hard and is making enormous progress. As a result of these early intervention investments, Ben continues to reach major milestones which will fundamentally change his life and allow him to fully participate in his community. Easter Seals asks that you increase funding by $20 million for the Part C Early Intervention grants to $458,498,000 in FY 2015 so more children like Ben can access the services and supports they need when they need them to succeed.

MEET ELIJAH: Elijah achieved academic success most parents dream for their children. He was high school class valedictorian and a college honors student with a Master's Degree. However, his transition into the workplace has been challenging. He can't find a job. Elijah lives with Asperger's syndrome and, in fact, benefited from early intervention services through Easter Seals when he was a child. However, Elijah has struggled during this adult transition, particularly in job interviews where the repetitive nature of Asperger's syndrome makes it challenging for him to stay succinct and on track. Elijah is not alone. The Government Accountability Office (GAO-12-594) found that students with disabilities face "several longstanding

challenges" during their transition from high school into postsecondary education or the workforce. Among the challenges the GAO cited was accessing services, such as transportation education and travel instruction. The U.S. Department of Education has proposed in its FY 2015 budget to test a coordinated model of transition planning, services, and supports through a new Transition Model System (TMS). The goal of TMS is to help address the many challenges faced by youth with disabilities like Elijah. Easter Seals asks that the subcommittee to fully support the Administration's FY 2015 funding request of $15,000,000 for the Transition Model System and asks that you include report language to strengthen the connection and importance of transportation education and travel instruction within TMS to increase and improve postsecondary outcomes for students with disabilities.

MEET DONALD: Donald was a proud veteran of the Air National Guard but – at age 48 – he found himself unemployed for more than five years and living on the street. Despite the national push to end homelessness among veterans, far too many men and women who served our nation like Donald did are among the ranks of America's homeless. Donald was connected to Easter Seals, who utilized the holistic, supportive services care coordination model used in the Department of Labor's Homeless Veterans Reintegration Program (HVRP) to help get Donald back on his feet. Easter Seals connected Donald to transitional housing, provided him with a monthly bus pass so he could easily attend required meetings and trainings, and linked him to the local U.S. Department of Veterans Affairs medical center for other services. Donald also received individualized training and assistance in creating a resume and cover letter and in updating his job search, networking and interview skills. Based on his strengths and employment background, Easter Seals assisted Donald in a series of temporary jobs through staffing agencies, one of which turned into a full time permanent job, with benefits, at a local manufacturing company. Donald cited "networking skills, online job search assistance, resume update, housing stabilization, reliable transportation, and encouragement" as key Easter Seals HVRP services that helped him get employed again. HVRP is the only federal nationwide program focusing exclusively on the employment of veterans who are homeless. The program works, in large part, due to the holistic, person-centered care coordination model that Easter Seals has used for several decades in helping individuals with

disabilities achieve their dreams. Easter Seals asks that the subcommittee supports the authorized level of $50,000,000 for HVRP in FY 2015.

Thank you for the opportunity to share with you Easter Seals' appropriations priorities for the fiscal year 2015 Labor, Health and Human Services, Education, and Related Agencies appropriations bill. We hope that you consider these programs and the thousands of people with disabilities, veterans and older adults who are fully participating and contributing to their communities as a result of these early federal investments that continue to pay dividends. Thank you again for your time and consideration.

Statement of Dr. Lawrence E. Cornett
Vice President of Research
University of Arkansas for Medical Sciences

Submitted to the House Appropriations Committee
Subcommittee on Labor, Health and Human Services, and Education
March 28, 2014

Mr. Chairman and Members of the Subcommittee; thank you for the opportunity to submit this statement regarding FY 2015 funding for the National Institutes of Health's Institutional Development Award or "IDeA" Program. The IDeA program is funded by NIH's National Institute of General Medical Sciences (NIGMS), and was authorized by the 1993 NIH Revitalization Act (P.L. 103-43). I submit this testimony on behalf of the Coalition of EPSCoR/IDeA States[1] and the University of Arkansas for Medical Sciences. The Coalition of EPSCoR/IDeA States respectfully requests that the Subcommittee provide $310 million for the IDeA program in FY 2015.

I would first like to provide some basic information about the IDeA program. IDeA 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. The program funds only merit-based, peer-reviewed research that meets NIH research objectives. While IDeA was authorized by the 1993 NIH Revitalization Act (P.L. 103-43), sizable increases in funding only began in FY 2000. The program then grew rapidly, due in large part to the

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[1] Alabama, **Alaska, Arkansas, Delaware,** Guam, **Hawaii, Idaho,** Iowa, **Kansas, Kentucky, Louisiana, Maine, Mississippi,** Missouri, **Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oklahoma, Puerto Rico, Rhode Island, South Carolina, South Dakota,** Tennessee, Utah, **Vermont,** Virgin Islands, **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.

thoughtful actions of this Subcommittee. This funding permitted the initiation of two program elements: COBRE and BRIN/INBRE.

The first was the COBRE program or "Centers of Biomedical Research Excellence," which are research clusters targeting specific biomedical research problems. The second IDeA program 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 universities and primarily undergraduate colleges. The BRIN grants underwent competitive renewals in 2004 under the new name of "IDeA Networks of Biomedical Research Excellence," or INBRE.

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 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.

The INBRE program is designed to increase the pipeline of outstanding students and enhances the quality of science faculty in the IDeA states by research-intensive networking with 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. As you can see, these two programs play complementary roles in developing research capability and human capital in biomedical fields in the IDeA states.

Impact of the IDeA Program on Arkansas

Arkansas is a rural state with persistent health disparities. The state has a single academic health center, the University of Arkansas for Medical Sciences (UAMS), with two affiliated hospitals staffed by UAMS faculty; Arkansas Children's Hospital and the Veteran's Administration Medical Center. The IDeA Program has had a positive impact on the ability of these institutions to address the state's health disparities. Since 2001, Arkansas has received support from the IDeA Program through the INBRE and COBRE mechanisms.

The Arkansas INBRE is a statewide network of research intensive and primarily undergraduate institutions with an overall goal of expanding biomedical research capacity in the state. The impact of the Arkansas INBRE has been far-reaching and has ranged from improving research core facilities at UAMS and the University of Arkansas to creating a joint graduate program in bioinformatics that is addressing the nation's shortage of trained individuals to analyze and interpret genomic data. In addition, the Arkansas INBRE has provided opportunities for students and faculty from primarily undergraduate institutions to participate in biomedical research that addresses human health problems. Some Arkansas INBRE supported undergraduate faculty now have independent research programs of their own and many students have gone on to graduate school and are now pursuing research careers.

The three COBRE-supported Centers in Arkansas collectively have made significant progress in developing biomedical research capacity in the State. The Center for Protein Structure and Function has supported the hiring of 15 faculty members and developed state-of-the-art capacity in protein analytic techniques. Center investigators have contributed significantly to the advancement of their field by

publishing 376 articles in peer-reviewed journals and have brought to the state more than $80 million in federal grant support. The Center for Translational Neuroscience established eight specialized core facilities that support research addressing neurological disorders such as Alzheimer's Disease, multiple sclerosis, and amyotrophic lateral sclerosis. Center investigators have published over 350 scientific articles and have been awarded more than $32 million in new grant support. The Center has developed a telemedicine core facility that supports the Pediatric Physician Learning and Collaborative Education (Peds PLACE) Program. Since the inception of Peds PLACE infant mortality in Arkansas has declined from 8.5/1000 live births in 2006 to 7.0/1000 live births in 2011. The newest COBRE program in Arkansas, the Center for Microbial Pathogenesis and Host Inflammatory Responses is relatively new; established in 2012, but has already recruited two new faculty and supports research projects that address new approaches to combating human infectious diseases.

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. Together, the 23 States and Puerto Rico that comprise the IDeA community secured just 5% of the total NIH budget in FY 2011. With over 22% of the Nation's population living in the EPSCoR/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 2013 total NIH funding to the IDeA community has risen to $1.5 billion. This is evidence that the program is working and that the IDeA states are moving in the right direction. To put the value of the IDeA investment into perspective, the overall FY 2014 IDeA budget, $273.325 million, for 23

states and Puerto Rico, pales in comparison to the $606.8 million in NIH funding that one institution in one single non-IDeA state received in FY 2012. In FY 2012, the top seven states with NIH funding received over a $1 billion each, and California alone received over $3.5 billion.

We request that this committee recommend the program to be funded in FY 2015 at $310 million. As you know, the EPSCoR/IDeA Coalition has maintained that IDeA program should constitute at least 1% of the total NIH budget. This level of funding would restore and continue funding for COBRE and INBRE, provide funding for the IDeA Program Infrastructure for Clinical and Translational Research (IDeA-CTR) program, and provide co-funding which would allow researchers and institutions to merge with the overall national biomedical research community.

On behalf of UAMS, I express gratitude to this Subcommittee for the efforts it has made over the years to provide increased funding for IDeA, in particular this committee's work to ensure the successful inclusion of a $50 million increase for the program in FY 2012. I hope that you will continue to invest in this program, which is so important to almost half of the states in the Union. 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 EPSCoR/IDeA Coalition, the University of Arkansas for Medical Sciences (UAMS) and our partner institutions across Arkansas, I thank the Subcommittee for the opportunity to submit this testimony.

ANSR AMERICANS FOR NURSING SHORTAGE RELIEF

Christine Murphy, ANSR Alliance Co-Chair
Senior Public Policy Specialist
National League for Nursing

Wade Delk, ANSR Alliance Co-Chair
Government Affairs Director
American Society for Pain Management Nursing
& International Nurses Society on Addictions

Testimony of the Americans for Nursing Shortage Relief (ANSR) Alliance Regarding Fiscal Year 2014 Appropriations for HRSA's Title VIII Nursing Workforce Development Programs and Nurse Managed Health Clinics

March 25, 2014

The organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony recommending $251 million for the Title VIII Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) and $20 million for the Nurse Managed Health Clinics as authorized under Title III of the Public Health Service Act. We represent a diverse cross-section of health care and other related organizations, health care providers, and supporters of nursing issues (http://www.ansralliance.org/Members.html) that have united to address the national nursing shortage. ANSR stands ready to work with Congress to advance programs and policy that will ensure our nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century.

The Nursing Shortage

Nursing is the largest health care profession in the United States and work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, schools, and hospitals. According to the U.S. Bureau of Labor Statistics, employment of registered nurses is projected to grow 19 percent from 2012 to 2022 - faster than the average for all occupations - resulting in 526,800 new jobs. This growth will occur for a number of reasons, including an increased emphasis on preventative care; growing rates of chronic conditions, such as diabetes and obesity; and demand

for healthcare services from the baby boomer population, as they live longer and more active lives. The Title VIII Nursing Workforce Education Programs will help fill these vacancies by supporting training programs designed to meet these health care needs.

The Title VIII Nursing Workforce and Education programs provide training for entry-level and advanced degree nurses to improve the access to, and the 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 that, between FY 2005 and 2010, supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions and health care facilities.

The Desperate Need for Nurse Faculty

Nursing vacancies exist throughout the entire health care system, including long-term care, home care and public health. 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.

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. 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 that they are accepted.

ANSR 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 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 Nursing Supply Impacts the Nation's Health and Economic Safety

The demand for primary care services in the US is expected to increase over the next few years, particularly with the aging and growth of the population. One study projects that by the year 2019, the demand for primary care in the United States will increase by between 15 million and 25 million visits per year. HRSA estimates that more than 35.2 million people living within the 5,870 Health Professional Shortage Areas nationwide do not currently receive adequate primary care services. Research suggests that nurses and other health professionals are trained to and already do deliver many primary care services and may therefore be able to help increase access to primary care, particularly in underserved areas.

ANSR applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. For 50 years, the Title VIII Nursing Workforce Development Programs have responded to the nation's evolving workforce needs by providing education and training opportunities to nurses. These programs are the only federal programs focused on filling gaps in the supply of nurses not met by traditional market forces, as well as producing a work-

force prepared to care for the nation's increasingly diverse and aging population. Numerous studies have demonstrated that the Title VIII programs graduate more minority and disadvantaged students more likely to serve in community health centers as well as rural and underserved areas. In a difficult economy, the Title VIII Nursing Workforce Education Programs help schools offer scholarships and affordable loans to nursing students, making such educational opportunities available to aspiring nurses of all backgrounds. By guiding job seekers to high-demand nursing jobs, the programs fulfill both their individual career goals and a community's health needs.

Summary

HRSA's Title VIII Nursing Workforce Education programs contribute to a sufficient nursing workforce to meet the demands of a highly diverse and aging population is an essential component to improving the health status of the nation and reducing health care costs. While the ANSR Alliance understands the immense fiscal pressures facing the nation, we respectfully urge support for $251 million in funding for Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at HRSA and $20 million for the Nurse Managed Health Clinics under Title III of the Public Health Service Act in FY 2015. We look forward to working with the Subcommittee to prioritize the Title VIII programs in FY 2015 and the future.

List of ANSR Member Organizations:

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Nurse Practitioners
American Academy of Nursing
American Association of Nurse Anesthetists
American Association of Nurse Assessment Coordination
American Association of Occupational Health Nurses
American College of Nurse-Midwives
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

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Association for Radiologic & Imaging Nursing
Association of Pediatric Hematology/Oncology Nurses
Association of State and Territorial Directors of Nursing
Association of Women's Health, Obstetric & Neonatal Nurses
Citizen Advocacy Center
Dermatology Nurses' Association
Developmental Disabilities Nurses Association
Emergency Nurses Association
Infusion Nurses Society
International Association of Forensic Nurses
International Nurses Society on Addictions
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 Orthopedic Nurses
National Association of Registered Nurse First Assistants
National Association of School Nurses
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 Student Nurses' Association, Inc.
Nurses Organization of Veterans Affairs
Pediatric Endocrinology Nursing Society
Preventive Cardiovascular Nurses Association
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 OF
MICHELE JOLIN, MANAGING PARNTER, AMERICA ACHIEVES
BEFORE THE
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES AND EDUCATION

March 28, 2014

Chairman Kingston and Ranking Member DeLauro:

Results for America (RFA), an initiative of America Achieves, is pleased to present our recommendations for Fiscal Year 2015 to the House Appropriations Subcommittee on the Departments of Labor, Health and Human Services, and Education.

The attached letter and table outline the evidence-based policies and programs RFA and our coalition partners are requesting from your Subcommittee for Fiscal Year 2015 to help improve outcomes for young people, their families, and communities.

Over the last several years, all levels of government have taken critical steps to change the way taxpayer dollars are invested to ensure limited resources are driven toward high-impact solutions that get results. To significantly improve outcomes for young people, their families, and communities in the context of constrained resources and mounting demands, the federal government should identify and invest in "what works," and be a catalyst for, and funder of, effective and innovative solutions that produce greater social impact. While public debate focuses on more or less resources, it is critical to

identify how to get better results from existing resources. This approach has a strong history of bipartisan support. President George W. Bush's Administration put a priority on improving the performance of federal programs and encouraged more rigorous evaluations to assess their effectiveness. The Obama Administration has built on this effort by supporting an increasing number of evidence and evaluation-based policies and programs. Mayors and governors from both parties across the country are also increasingly using data and evidence to steer public dollars to more effectively address needs in their communities and states.

I want to thank you for the positive steps you have taken over the last several years toward building a strong evidence-based, results-driven policy agenda and look forward to working with you in the months and years ahead.

On March 13, 2014, the following 72 organizations sent a letter to Chairwoman Mikulski, Chairman Rogers, and Ranking Members Shelby and Lowey requesting bill and report language to invest federal funds in what works. The letter and a summary of our recommendations for Fiscal Year 2015 for the House Appropriations Subcommittee on the Departments of Labor, Health and Human Services, and Education follow:

March 13, 2014

INVEST IN WHAT WORKS

Dear Chairwoman Mikulski, Chairman Rogers, Ranking Member Shelby, and Ranking Member Lowey:

We are writing to urge you to include the attached "Invest in What Works" provisions in the subcommittee appropriations bills and reports for the Departments of Labor, Health and Human Services, Education, and Related Agencies, and the Departments of Commerce, Justice, Science, and Related Agencies for fiscal year 2015.

America is facing enormous social and economic shifts, budget constraints at all levels of government, significant demographic changes, and an increasingly globally competitive, changing workforce. While the recently-enacted FY14 omnibus appropriations law includes an unprecedented commitment to evidence and evaluation, we must continue to focus on improving the ways in which federal taxpayer dollars are spent in FY15 and beyond in order to be able to significantly improve outcomes for young people, their families, and communities.

We thank you for the positive steps you have taken over the last several years toward building a strong evidence-based, results-driven policy agenda and encourage you to reaffirm your commitment to improving outcomes for all Americans by incorporating the attached "Invest in What Works" recommendations in the fiscal year 2015 appropriations bills and committee reports.

Thank you for your consideration of our requests.

Sincerely,

AdvancEd
AIDS United
Alliance College-Ready Public Schools
Amos House (RI)
Aspire Public Schools
BELL
Breakthrough Schools
Brighton Center, Inc. (KY)
Capital Impact Partners
Center for Employment Opportunities
Center for Research and Reform in Education, Johns Hopkins University
Champlain Housing Trust (VT)
Cincinnati Works
Citizen Schools
City First Homes and City First Enterprises (DC)
City Year, Inc.
CLUE (Comunidades Latinas Unidas En Servicio) (MN)
CommonBond Communities (MN)
Communities in Schools
Community Action Duluth
Community Training and Assistance Center (CTAC)
Congreso de Latinos Unidos Inc.
CSH
Edna Martin Christian Center (IN)
Education Northwest
Emerge Community Development (MN)
Family Resources Community Action (RI)
Focus: HOPE (MI)
Gestalt Community Schools
Greater Southwest Development Corporation (IL)
GreenLight Fund
Home Start, Inc. (CA)
Housing Leadership Council, Inc. (FL)
IDEA Public Schools
Jane Addams Resource Corporation (IL)
KIPP
Knowledge Alliance
LISC
Metropolitan Family Services (IL)
Mile High United Way
National Forum to Accelerate Middle-Grades Reform
National Fund for Workforce Solutions
New Profit Inc.
North County Lifeline (CA)
Operation ABLE (MI)
Project for Pride in Living, Inc. (MN)
Providence Housing Authority
Reading Partners
REDF
Results for America
Rocketship Education
Rubicon Programs
Safer Foundation (IL)
Santa Maria Community Services (OH)
SER-Jobs for Progress of the Texas Gulf Coast, Inc.
SER Metro Detroit, Jobs for Progress, Inc.
Southeast Community Services Inc. (IN)
Southwest Solutions (MI)
StriveTogether
Success for All Foundation
Teach For America
Teach Plus
The SEED Foundation
Turnaround For Children
United Way of Greater Cincinnati
United Way for Southeastern Michigan
Urban Alliance
U.S. Soccer Foundation
Venture Philanthropy Partners
Volunteers of America Texas Inc.
Year Up
Youth Villages

RECOMMENDATIONS FOR FISCAL YEAR 2015	
U.S. DEPARTMENT OF LABOR	
Workforce Innovation Fund - with up to $10,000,000 for Pay for Success initiatives	$60,000,000
Agency-Wide Evaluation Set-Aside - 1% of discretionary funds to be used by the Chief Evaluation Office for program evaluations	
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES	
Head Start Designation Renewal System – set-aside within the total provided for Head Start	$25,000,000
Mental Health Service Block Grant Program - at least 5% set-aside for evidence-based programs to address the needs of individuals with early serious mental illness	
U.S. DEPARTMENT OF EDUCATION	
First in the World - with $20,000,000 set-aside for minority-serving institutions	$100,000,000
Investing in Innovation (i3) – language directing the Department to provide continuation grants to certain current i3 grantees that are demonstrating strong interim outcomes but have not had sufficient time to achieve their program goals	$215,000,000
Replication and Expansion of High Quality Charter Schools – set-aside within the total provided for the Charter School Program	$75,000,000
Title II-A - Effective Teachers and Leaders - language requiring the Secretary to set aside 25% of ESEA Title II-A funds for competitive grants to states, high need local school districts, and national non-profit organizations, including 10% set-aside for the Supporting Effective Educator Development (SEED) program	
Titles I and II - language directing states to set-aside 1% of Title I and II funds, prior to distribution to local school districts (LSD), and to award these funds on a competitive basis to the 25% of LSD's with the highest poverty levels through a tiered funding frame-work	
IDEA Results-Driven Accountability Grants – set-aside to implement promising evidence-based reforms	$100,000,000
Agency-Wide Evaluation Set-Aside - 1% of discretionary funds (not including Pell Grants) for program evaluations	
Title II - Whole School Reform – language allowing local school districts to use School Improvement Grants to implement a whole-school reform strategy for a school using an evidence-based strategy that ensures whole-school reform is undertaken in partnership with a strategy developer offering a whole-school reform program that is based on at least a moderate level of evidence that the program will have a statistically significant effect on student outcomes as defined by the Department's General Administrative Regulations	
CORPORATION FOR NATIONAL AND COMMUNITY SERVICE	
Social Innovation Fund – including up to 20% set-aside for Pay for Success initiatives and language directing CNCS to (1) provide renewal grants to current SIF grantees that are demonstrating significant interim outcomes but have not had sufficient time to achieve their program goals and (2) permit current SIF grantees to be eligible to apply for additional SIF funds for projects not currently funded by SIF	$80,000,000
GENERAL PROVISION	
Performance Partnership Pilot – language establishing up to 10 Performance Partnership Pilots to improve outcomes for disconnected youth	

March 28, 2014 Submitted for the Record

Leslie Ritter, Director of Government Affairs, Society for Women's Health Research (SWHR)

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

The Society for Women's Health Research (SWHR) is pleased to have the opportunity to submit the following testimony urging renewed investment in scientific and medical research within the Department of Health and Human Services (HHS). For almost 25 years, our organization has been considered the thought leader in research on biological differences in disease and is dedicated to transforming women's health through science, advocacy, and education. We believe that a robust federal research agenda that is inclusive of women's health research is critical for the U.S. to meet the needs and expectations of its citizens. We request that for fiscal year (FY) 2015, Congress fund the following agencies and programs at the following levels:

- Agency for Healthcare and Research Quality –$471 million
- Centers for Disease Control and Prevention- $6.904 billion
- Health Resources Services Administration- $6.113 billion
- National Institutes of Health -$32 billion
- Substance Abuse and Mental Health Services Administration- $3.6 billion
- Office of Research on Women's Health at NIH-$42 million
- HHS Office of Women's Health- $35 million

SWHR remains concerned with the ramifications of the Budget Control Act and sequestration. Funding levels for Department of Health and Human Services (HHS), were significantly cut and those agencies that fall underneath the umbrella of HHS; The Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Health Resources Services Administration (HRSA), National Institutes of Health (NIH), Substance Abuse and Mental Health Services Administration (SAMHSA), all play vital roles in improving and

protecting the health of Americans but are forced to do more with less funding. **Continued cuts to public health agencies decrease public health emergency preparedness and response capabilities, reducing funding for states to monitor air quality and offer mental health services, and increasing the risk for infectious disease outbreaks. These are essential public health services that save lives and protect our health.** Currently, healthcare spending is the largest driver of the federal deficit. By 2021, estimates indicate that this spending will account for nearly one-fifth of the U.S. economy. Proper and sustained Congressional investment in medical and scientific research can ultimately save valuable healthcare dollars that are wasted on inappropriate and ineffective treatment. We realize that the current budgetary environment limits the amount of monies available for a substantial increase; however, the benefit from every dollar invested in medical research outweighs the cost many times over and is, perhaps, the single most cost effective strategy in reducing our federal deficit.

Past investments in medical research have allowed scientists to begin unraveling the biologic and genetic underpinning of disease. This research has shown that biological sex impacts every organ of the body, and plays an important role in disease susceptibility, prevalence, time of onset and severity. Sex differences are evident in all major disease categories, including cancer, obesity, and heart disease. These differences are also evident in drug absorption, distribution, metabolism and elimination. The medical community has now begun to tailor treatments to meet the needs of individual patients, taking the first step towards truly personalized medicine.

National Institutes of Health- NIH serves as the America's premier medical research agency and is the largest source of funding for biomedical and behavioral research in the world. Many of the

medical advances in recent decades are direct results from investments in the agency. Unfortunately, years of flat-funding, without controlling for rising inflation, has meant that NIH's overall budget has decreased by 10% between 2004 and 2014, and its purchasing power has decreased by 22%. This number does not just impact NIH's campus in Maryland. Approximately 85% of NIH funding is spent in communities across the country, creating jobs at more than 3,000 universities, medical schools, teaching hospitals, and research institutions. In 2013, NIH funded 750 fewer grants than in 2012 and grant funding fell to an all-time low of 20%. A shrinking number of available grants put scientists out of work. With limited opportunities for research funding, scientists have little choice than to pursue opportunities outside of academic research in the U.S, resulting in the loss of skilled bench scientists and researchers to Asia, the European Union and the United Kingdom, who continue to heavily invest in research.

Unfortunately, the Administration's request of a 0.7% increase doesn't make much headway in reversing the $1.5 billion cut the agency sustained under sequestration in FY 2013, nor does it keep up with biomedical inflation rate, projected by the HHS's Biomedical Research and Development Price Index, to be 2.2%. Once that inflation rate is taken into account, the Administration's budget request results in another cut to the Agency. **SWHR recommends that Congress set, at a minimum, a budget of $32 billion for NIH for FY 2015. Further we recommend that Congress expand NIH's mandate on the inclusion of women in basic research to include women in all phases of basic, clinical and medical research.** Current practice only mandates sufficient female subjects only in Phase III research, and researchers often miss out on the chance to look for variability by sex in the early phases of research, safety

and effectiveness is determined.

Federal offices of women's health- The offices of women's health within the federal health agencies do critical work, both individually and in collaboration with other offices and federal agencies, to ensure that women receive the appropriate care and treatments in a variety of different areas. Under HHS, the agencies currently with offices, advisors or coordinators for women's health or women's health research include the AHRQ, CDC, FDA, HRSA, Indian Health Service (INS), and SAMHSA. These offices do important work, both individually and in collaboration with other offices and federal agencies to ensure that women receive the appropriate care and treatments in a variety of different areas. In a time of limited budgetary dollars, Congress should invest in these offices that promote working in collaboration with other agencies, which shares much needed expertise while avoiding unnecessary duplication. **SWHR recommends that these offices be sufficiently funded to ensure that these programs can continue to provide much needed services to women and their families in FY 2015.**

Office of Research on Women's Health - ORWH is the focal point for coordinating women's health and sex differences research at NIH, and supports innovative interdisciplinary initiatives that focus on women's health and sex differences research. ORWH promotes opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. The Building Interdisciplinary Research Careers in Women's Health (BIRCWH) is an innovative, trans-NIH career development program that pairs junior faculty with senior investigators in a mentored environment. Approximately 500 scholars, the majority of them female, have been trained at 39 centers and have produced approximately 5,000 publications.

ORWH's administrative supplements for research on sex and fender differences, a trans-NIH initiative to broaden the field of sex and gender differences research, adds new dimensions to on-going studies. The specialized centers of research on sex and gender factors affecting women's health (SCOR) are designed to integrate basic and clinical approaches to sex and gender research across scientific disciplines and has resulted in over 650 articles, reviews, abstracts, book chapters and other publications. **To allow ORWH's programs and research grants to continue make their impact on the research community, Congress must direct that NIH continue its support of ORWH and provide it with a $1 million dollar budget increase, bringing its FY2015 total to $42 million.**

Health and Human Services' Office of Women's Health- The HHS OWH is the government's champion and focal point for women's health issues. It works to address inequities in research, health care services, and public education gaps, which have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would be only more difficult and delayed. **Considering the impact of women's health programs from OWH on the public, we urge Congress to provide an increase of $1 million for this office, a total of $35.7 million for FY 2015.**

In conclusion, Mr. Chairman, we thank you and this Committee for its support for medical and health services research and its commitment to the health of the nation. We look forward to continuing to work with you to build a healthier future for all Americans.

AMERICAN
SOCIETY FOR
MICROBIOLOGY

Office of Public Affairs

Statement of the American Society for Microbiology
Submitted to the
House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
On the Fiscal Year 2015 Appropriation for the National Institutes of Health

March 26, 2014

The American Society for Microbiology (ASM), the largest single life science Society with over 39,000 members, wishes to submit the following comments and recommendations for the record on the FY 2015 budget for the National Institutes of Health (NIH). The ASM commends Congress for passage of the FY 2014 Omnibus Appropriations Bill which represents a step in the right direction although funding for NIH remains too low in view of the gaps in our knowledge of disease and the abundance of scientific opportunities that cannot be pursued because of lack of funding. The ASM recommends that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in the Nation's investment in medical research.

The ASM is very concerned about the future of biomedical research in the United States. NIH support for basic research is critical to health and security, job creation and growing the US economy. In FY 2013, the success rate for NIH research grant applicants fell to an historic low 16.8 percent. The average size of research project grants (RPGs) decreased to the lowest ever since 1999. During last year's sequestration, there were reports of delayed research projects, enforced layoffs of technical staff and waning innovation. Such stagnation undercuts biomedical research progress in the United States at a time when the opportunities are great and other nations are growing their investment in basic and translational biomedical research.

NIH is the primary supporter of biomedical research in the Nation. In 2012 alone, NIH funding supported more than 402,000 jobs and $57.8 billion in new economic activity nationwide. Among NIH's investments are those in the rapidly advancing field of genomics. A recent report from the nonprofit United for Medical Research (UMR) spotlighted the economics of federal investment in the human genome project, which has generated $965 billion in economic impact, more than 53,000 direct genomics related jobs and $293 billion in personal income.

Current trends in the Nation's R&D investments clearly do not bode well for future innovation and global competition. Federal R&D expenditures declined by 16.3 percent between fiscal years 2010 and 2013, while China's investment jumped more than 400 percent over the past decade. Since 2001, the US share of global R&D performed has decreased from 37 percent to 30 percent. The Science Coalition Report in 2013 highlighted the importance of federally funded university research in creating new companies and R&D jobs. The report profiles R&D companies launched by relatively small federal investment in university research, including NIH grants

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funding rapid pathogen detection technologies, vaccine development and advances in food and water safety.

Several UMR reports from last year underscore how NIH supported research can propel private sector growth and innovation. US biotech companies catalyzed by NIH funding illustrate the productive collaborations among NIH, university research scientists and the private sector. These companies are reshaping lucrative R&D sectors like gene sequencing and therapeutics for human disease, taking basic research to the marketplace. NIH support is responsible for several of *Science* magazine's top ten 2013 discoveries, all expected to return huge dividends, including the "breakthrough of the year" cancer immunotherapy, the new gene editing CRISPR technique and the astoundingly important human microbiome project.

Also included was the first use of structural biology techniques to custom design a powerful immunogen with vaccine potential, in this case against respiratory syncytial virus (RSV). Worldwide, about 64 million cases of RSV infection occur each year, responsible for 160,000 deaths, making it the most common cause of severe respiratory illness in infants and young children. There is no approved vaccine, but the team led by NIAID Vaccine Research Center identified 3-D structures of attachment sites on the virus surface and potent antibodies against those sites, offering new tools to develop new or improved vaccines.

NIH investments build the scientific foundation for the Nation's valuable biomedical R&D sector, which employs 7 million and exports $90 billion in goods and services. In 2013, all three recipients of the Nobel Prize in Physiology or Medicine and all three winners of the Nobel Prize in Chemistry had at some point received NIH funding (for a total of 144 NIH supported Nobel laureates). Four NIH funded scientists also won prestigious 2013 Lasker Foundation awards.

As the Nation's largest funder of biomedical research, NIH leads the Nation's efforts to discover new cures, preventions and therapies for difficult disease challenges by funding intramural and extramural projects to combat infectious diseases that kill millions of people worldwide. The National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of General Medical Sciences (NIGMS) contribute to new, paradigm shifting technologies like high throughput genomic sequencing, as well as new multidisciplinary research approaches like systems biology.

NIAID funded scientists have discovered therapies, vaccines, diagnostic tests and other biomedical tools that improve human health. Lifesaving examples are vaccines for rabies, meningitis, whooping cough, hepatitis A and B, chickenpox and pneumococcal pneumonia. Developing new influenza vaccines is a high priority for NIAID, which has supported a health provider consortium for clinical trials since the 1960s. The NIAID Vaccine Research Center's influenza research has produced multiple promising advances like a DNA vaccine against H5N1 avian influenza and it helped establish the Southeast Asia Influenza Clinical Research Network to address global influenza threats. Ongoing NIAID research is making progress toward the highly significant goal of a universal influenza vaccine that would confer decades long protection from any flu virus strain.

In February, NIAID reported on its latest contributions in the battle to halt antimicrobial resistance (AR) spreading among pathogens, which is creating ever more dangerous diseases like multidrug resistant gonorrhea and extensively drug resistant tuberculosis. Each year, there are 2 million drug resistant infections and 23,000 deaths in the United States. Annual costs are an estimated $20 billion in added healthcare and $35 billion in lost productivity. NIAID leads U.S. research against drug resistant pathogens, making major investments in basic, translational and clinical research. Results include advances in prevention, diagnosis and treatment of AR infections, as well as greater support for new drug discovery. The agency has helped support R&D of at least 25 percent of the antibiotics currently in clinical testing. Basic AR research funded by NIAID is detailing the ways that pathogens evade host defenses, to identify new therapeutic and diagnostic targets. Using the latest in technological tools, NIAID supported researchers are developing novel diagnostics platforms for more rapid and accurate detection of emerging AR infections. NIAID's expansive AR portfolio also includes vaccine development against increasingly common AR threats like drug resistant staph and gonorrhea bacteria.

One of NIAID's greatest challenges for the 21st century is developing defenses against familiar enemies, the world's three greatest microbial killers, HIV/AIDS, malaria and tuberculosis. Recent research advances include the following:

- A novel compound, from a new class of potential antimalarial drugs, appears effective against multiple life stages of the malaria causing *Plasmodium* parasite. Most antimalarials only target the parasite as it grows in the host's bloodstream, giving the parasite more chances to spread and acquire drug resistance.

- After designing nanoparticles loaded with copies of mutated HIV selected via computerized screening, scientists have activated host immune cells to produce VRC01 neutralizing antibodies. The approach offers a new tool to potentially reverse engineer neutralizing antibodies against HIV and other viruses.

- Using a systems biology approach, scientists have identified interactions among genetic regulators in *Mycobacterium tuberculosis* (Mtb), the bacterium that causes tuberculosis (TB). The results help explain how Mtb lies latent for long periods in otherwise healthy people, then becomes active and transmissible TB. About one third of the world's population is infected, making Mtb switches between different stages crucial to public health.

Research strategies clearly rely upon previous scientific successes. Ever shifting influenza viruses and steady evolution of AR pathogens illustrate how any effort must build upon the past, respond to the present and plan for the future. New microbial threats emerge as old threats persist, the recent spread of dengue fever, detection of influenza H7N9 last year and the newly emerging coronavirus caused Middle East respiratory syndrome (MERS). First identified in 2012, MERS-CoV infection has been implicated in 181 cases (as of February 4) and 79 deaths. With high mortality and no treatments, the disease's spread from the Middle East to Europe has health officials concerned. NIAID funded researchers now have reported some laboratory success using potential MERS-CoV therapy that combines two licensed antiviral drugs routinely used to treat diseases such as hepatitis C.

At NIGMS, microbial genetics and cell/molecular biology are principal research emphases, recognition that microbiology not only provides insights to human health and biology in general, but also stimulates innovation in US biotechnology. Each year, NIGMS awards more than 4,500 research grants and supports one fourth (~4,000) of the NIH supported technical trainees. NIGMS funded research has generated high value technologies like PCR, high throughput DNA sequencing, and the human genome project. The latest exciting biotech tool to emerge is CRISPR technology (Clustered Regularly Interspaced Short Palindromic Repeats, DNA loci in bacterial genomes), innovation that evolved from basic research in both phage biology and advanced computing genomics. With huge potential for improved genome editing essential to the biotech industry, today the CRISPR system is increasingly used in gene cutting and other customized gene targeting.

Without sustained NIH funding in diverse fields like microbiology, ASM strongly believes there will be fewer new discoveries and innovation in the United States. We urge Congress to build on bipartisan efforts to replace the random cuts of sequestration that have been devastating to basic research in the United States and to increase funding for the National Institutes of Health. Increased investment will enable the scientific progress that is needed to improve the health, security and economic growth of the country.

Testimony in Support of the State Paid Leave Fund

Submitted to the U.S. House of Representatives Committee on Appropriations

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

Eliza Townsend, Executive Director

Maine Women's Lobby

March 28, 2014

As the Executive Director of the Maine Women's Lobby, I respectfully urge the Committee on Appropriations to include the State Paid Leave Fund, administered through the Department of Labor, in the Fiscal Year 2015 Labor, Health and Human Services and Education bill. The bill should include the $105 million funding proposed in the President's budget. The State Paid Leave Fund would create a competitive federal grant fund designed to spur innovation among states interested in creating family and medical leave insurance (FMLI) programs, as well as those with established FMLI programs, and has the potential to help millions of American families, including thousands here in Maine maintain economic security.

The Maine Women's Lobby advocates on behalf of Maine's 678,000 women and girls. We know that economic security is the issue that affects all other aspects of a woman's life: her health, her ability to escape a violent relationship, her autonomy, and her children's prospects. Our state's poverty level for people over 65 is above the national average, and the majority of those poor elders are women. We support a variety of public

policy strategies that improve women's economic status, including having access to paid leave.

At some point in their working lives, almost all Americans will need to take time off to care for a new baby or adopted child, an ailing child or parent, or their own health. The Family and Medical Leave Act – the only federal law designed to help working people meet the dual demands of job and family – leaves out 40 percent of the workforce and guarantees only unpaid leave, which millions cannot afford to take. And only 12 percent of the U.S. workers currently have access to paid family leave through their employers. That means millions of workers who develop serious health conditions, have seriously ill family members or become parents are forced to choose between what is best for them and their families and income they need to cover basic expenses.

Family and medical leave insurance programs at the state level allow workers to pay a small portion of their wages each week for the guarantee that when they need it, they can receive a percentage of their wages while they have to take extended family or medical leave from work. These programs help working families stay afloat when they need time off to care for an ill family member, a new baby or their own health.

Three states – California, New Jersey and Rhode Island – have created family and medical leave insurance programs. Research has shown that paid leave programs contribute to increased family financial stability and improved child well-being, better

workforce outcomes for new parents, reductions in government public assistance expenditures, and cost-savings for businesses.

That's why there is broad support among the business community for paid family and medical leave programs. Businesses understand it's good for their bottom line. California employers report that the program has had a neutral or positive effect on employee productivity, profitability, and turnover, and most employers coordinate their own benefits with the state's PFL program. A 2011 study of California's FMLI program estimated that it would save employers $89 million a year. A recent Rutgers study shows that New Jersey's FMLI program has saved businesses money by improving employee retention, decreasing turnover costs, and improving productivity.

A federal grant program would help states with one-time start-up costs to develop and implement successful family and medical leave insurance programs that are so needed across the country. Once these insurance programs are up and running they become self-sustaining. Without this federal support, the initial capital needed to design and launch these programs would continue to act as a roadblock, despite broad public support.

This fund would benefit both states considering a family leave and medical insurance program and states with an existing FMLI program. States with established FMLI programs could apply for grants to increase awareness about and utilization of the program by conducting outreach to ensure eligible workers who have been paying into the program are accessing it when they need it. For many states considering programs, access

to competitive federal grants that help defray the one-time costs of designing and launching these insurance programs would provide a compelling incentive to states to innovate. In the case of the SPLF, a modest investment at the federal level would translate to significant impact for millions of families' economic security.

The Maine Women's Lobby is actively conducting research to lay the groundwork for and advance FMLI legislation. The prospect of the SPLF promises an incentive for our state to pass legislation, knowing we can tap federal dollars to support one-time, start-up costs that would otherwise be prohibitive.

In sum, there is tremendous support across the country for creating a new State Paid Leave Fund. Nearly a dozen states, including Maine, could immediately benefit from federal funds made available through a competitive grant program. I urge you to pass a budget bill with $105 million allocated for the State Paid Leave Fund to help states like Maine with programs that benefit working families, businesses, and the local economy.

Patricia Harrity

Executive Director

Northwestern Connecticut Area Health Education Center (AHEC)

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House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies Testimony for the Record

Funding of $75 Million for Title VII Area Health Education Center (AHEC) Program - Health Resources Services Administration, Department of Health and Human Services

My name it Tricia Harrity and I am the director of Northwestern Connecticut AHEC, serving greater northwestern Connecticut. Northwestern Connecticut AHEC is one of the four regional centers that make up the Connecticut AHEC Network with a program office at the University of Connecticut School of Medicine. Northwestern Connecticut AHEC is part of the national network of 200+ AHEC centers that serve communities across the nation. AHEC has 30 years of experience building the country's healthcare workforce. Linking local communities to health professions education, AHECs assure that all Americans have access to health professionals and quality health care.

America's health care system is being challenged to make changes that will achieve the ambitious Triple Aim of Better Health, Better Care and Lower Costs. AHECs are well positioned to respond to this challenge. AHEC centers and programs based in widely diverse communities across the nation effectively respond to this challenge with services and programs which directly address the changing health care environment. For example, the Connecticut

AHEC Network's **Urban Service Track** is a best practice for Inter-Professional Education. The Urban Service Track trains students from five disciplines (medicine, dental medicine, nursing, physician assistant and social work) in inter-professional teams teaching them to work collaboratively to better serve the needs of patients. Urban Service Track scholars have chosen to dedicate their education and practice to serving urban under-served area. Another example of AHECs responding effectively and efficiently to emerging national health care priorities is the **Youth Mental Health First Aid Corps** launch by Northwestern Connecticut AHEC just nine months after President Obama called for widespread implementation of the Youth Mental Health First Aid program. The Youth Mental Health First Aid Corps engages AHECs across the nation in the implementation of the Youth MHFA certification classes for community members who work with adolescents as a strategy to improve access to mental health care services for youth who are experiencing a mental health care challenge or illness.

What do AHECs do?

- *Community based health care workforce training, with an emphasis on primary care.*
- *Training, teaching, recruiting and supporting the health professions workforce and rural and underserved areas.*
- *Fostering a diverse health professions workforce that reflects the nation's population.*
- *Prepare health professionals to expand collaborative practice and team models of care.*

AHECs provide services that respond to key needs of the changing healthcare landscape

- *Integrating public health and primary care*
- *Placing medical students in community-based primary care settings*

- *Coordinating clinical placements of nurses and health professions students in rural and underserved areas*
- *Increasing access to healthcare and insurance for those that need it most*
- *Increasing skills in team based care and better care coordination through Inter-professional Education*
- *Focusing on health professions training that improves patient safety and clinical outcomes.*

AHEC's diverse workforce has an excellent track record of recruiting, mentoring and training students from underrepresented minority, rural and disadvantaged populations. The people who work in AHECs are as diverse as the people we work with. AHEC's collaborations with National Health Service Corps, National Association of Medical Minority Educators, National Rural Health Association, Corporation for National and Community Service and many others, along with over 200 center locations in communities where providers, students and their families live, provide AHECs with the unique ability to understand and respond to their challenges.

I hope you agree with me that AHEC is a critical link between communities and a high-quality health care workforce for the future thus warranting FY15 funding of $75 million.

Respectfully Submitted,

Tricia Harrity

Testimony of the Physician Assistant Education Association (PAEA)
Concerning HRSA's Title VII Health Professions Programs

Submitted for the Record to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education and Related Agencies – March 25, 2014

Submitted by: Anthony Miller, M.Ed., PA-C Chief Policy and Research Officer
tmiller@paeaonline.org, 703-667-4339

On behalf of the 187 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) 2015 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act. PAEA supports funding of at least $266.4 in FY 2015 for 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). We also request $12 million of that funding support PA programs operating across the country. This is the only designated source of federal funding for PA education and is crucial to the U.S. PA education system's ability to meet the demand for education and to continue to produce highly skilled physician assistants ready to enter the health care workforce in an average of 26 months. The way that PAs are educated in America – the caliber of our institutions and the expertise of our educators – is the gold-standard throughout the world and that distinction must be maintained in this period of unprecedented patient need and rapid growth within the PA profession.

Need for Increased Federal Funding

The unmet need for primary care services in the United States is well documented, and only expected to grow as Baby Boomers age and the Affordable Care Act is fully implemented. The very parameters of access and health care quality are rapidly evolving. Yet the one constant in our health care system remains the need for qualified health care providers in numbers sufficient to meet demand, and primary care has been clearly identified as the critical entry point into the health care system where that access must be guaranteed. The PA profession was created specifically to address a shortage of primary care physicians almost fifty years ago, and today's PAs stand ready to help address the challenges our nation faces in primary care. The effectiveness of physician assistants is well-documented by studies showing better patient access, especially for Medicaid patients, high patient satisfaction, more frequent patient education, and health care outcomes similar to physicians. Importantly, PAs could play an even larger role in high-quality, cost-effective care if offered appropriate financial support and through innovations in the PA education system.

Like physicians, the PA profession also faces a shortage of graduates that will hinder its ability to help fully address the primary care issue in the United States. Without new solutions, at the current output of approximately 7000 graduates from PA programs per year, these shortages will persist, particularly in the rural and underserved communities where care is needed the most. Title VII is the only funding source that provides direct support for PA programs and plays a crucial role in developing and supporting the education system's ability to produce the next generation of these advanced practice clinicians.

Background on the Profession

Since the 1960s, PAs have consistently demonstrated they are effective partners in health care, readily adaptable to the needs of an ever-changing delivery system. Physician assistants are licensed health professionals with advanced education in general medicine that practice medicine as members of the healthcare team. They provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings, including prescriptive authority in all 50 states, the District of Columbia, and Guam. PAs practice medicine to the extent allowed by law and within the physician's scope of practice and their combination of medical training, advanced education, and hands-on experience allows PAs to practice with significant autonomy, and in rural and other medically underserved areas

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where they are often the only full-time medical provider. The profession is well established, yet nimble enough to embrace new models of care, adopt innovative approaches to training and education, and adapt to health system challenges. The PA practice model is, by design, a team-based approach to patient-centered care where the PA works in tandem with a physician and other health professionals. This PA practice approach to quality care is uniquely aligned with the patient-centered, collaborative, interprofessional and outcomes-based care models transforming the U.S. health care system.

PA Education: The Pipeline for Physician Assistants
There are currently 187 accredited PA education programs in the United States—a 23% increase over the past five years; together these programs graduate over 7,000 PA students each year. PAs are educated as generalists in medicine and that training gives them the flexibility to practice in more than 60 medical and surgical specialties. More than one third of PA program graduates are working in a primary care specialty.

The average PA education program is 26 months in length and includes one didactic year in the classroom, and another year devoted to clinical rotations. Most curricula include 340 hours of basic sciences and nearly 2,000 hours of clinical training, second only to physicians in time spent in clinical study.

As of today, approximately 65 new PA programs are in the pipeline at various stages of development and moving toward accredited status. The growth rate in the applicant pool is even more pronounced. Since its inception in 2001 through the most recent application cycle, the Centralized Application Service (CASPA) used by most programs grew from 4,669 applicants to over 20,000. As of March 2014, there were 19,968 applicants to PA education programs, a 36% increase in CASPA applicants over the past five years alone.

The PA profession is expected to continue to grow as a result of the projected shortages of physicians and other health care professionals, the growing demand for care driven by an aging population, and the continuing strong PA applicant pool. Accordingly, 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—if appropriate resources are available to support the education system behind them.

AREAS OF ACUTE NEED

Faculty Shortages
Faculty development is one of the profession's critical needs and educators are an often overlooked element to developing an adequate primary care workforce. Nearly half of PA program faculty are 50 years or older and the PA teaching profession faces large numbers of retirements in the next 10-15 years. An interest in education must be developed early in the educational process to ensure a continuous stream of educators, and to do so, we must alleviate the significant loan burdens that prevent many physician assistants from entering academia. In order to attract the most highly qualified faculty, PA education programs must have the resources to help clinicians transition into education, including curriculum development, teaching methods, and laboratory instruction. Most educators come from clinical practice and these non-clinical professional skills are essential to a successful transition from clinical practice to a classroom setting. Without federal support, we will face an impending shortage of educators who are prepared for and committed to the critical teaching role that will ensure the next generation of skilled practitioners.

Clinical Site Shortages
Outside of the classroom, PA education faces additional challenges in meeting demand. A lack of clinical sites for PA education is hampering PA programs' ability to produce PAs at the pace needed to meet the demand for primary care in the U.S. This shortage is caused by two main factors: a shortage of medical professionals willing to teach

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students as they are cycling through their clinical rotations (preceptors), and a lack of sites with the physical space to teach.

This phenomenon is experienced throughout the health professions, and is particularly acute in primary care. It has created unintentional competition for clinical sites and preceptors within and among PAs, physicians and advance practice nurses. Federal funding can help incentivize practicing clinicians to both offer their time as preceptors, and volunteer their clinical operations as training grounds for PAs and other health professionals to train together and directly interact with patients as a team. PAEA believes that interprofessional clinical training and practice are necessary for optimum patient care and will be a defining model of health care in the U.S. in the 21st century. We can only make that a reality if we begin to build a sufficient network of health professionals who are willing to teach the next generation of primary care professionals—that approach will benefit PAs as well as the future physicians, nurses and other clinicians that comprise the full primary care team.

Enhancing Diversity

Workforce diversity, and practice in underserved areas are key priorities identified by HRSA and are consistent with those of PAEA. It is increasingly important for patient care quality 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 committed to attracting students from underrepresented minority groups and disadvantaged backgrounds into the profession, including veterans who have served our country and desire to transition to civilian health professions. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care, and PA programs are looking for unique ways to recruit diverse individuals into the profession, and sustain them as leaders in the education field. If we can provide resources to schools that are particularly poised to improve their diversity recruitment efforts and replicate or create best practices including transition programs for our veterans, we can begin to address this systemic need.

In order to leverage the efforts of PA programs through Title VII funding to increase workforce diversity in the PA profession, PAEA also supports the restoration of funding for the Health Careers Opportunity Program (HCOP), and increased funding for the Scholarships for Disadvantaged Students and National Health Service Corps. Historically, access to higher education has been constrained for individuals from disadvantaged backgrounds. These programs help to provide a clear path for students who might not otherwise consider a physician assistant career.

Title VII Funding

Title VII funding fills a critical need for curriculum development, faculty development, clinical site expansion and diversification of the primary care workforce–areas that if appropriately supported can help ensure the PA profession realizes its full promise in the U.S. health care system. These funds enhance clinical training and education, assist PA programs with recruiting applicants from minority and disadvantaged backgrounds, and enable 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 with the most urgent need for access to care.

Title VII support for PA programs was strengthened in 2010 when Congress enacted a 15 percent allocation in the Appropriations process specifically for PA programs working to address the health provider shortage. This funding has enhanced capabilities to train a growing PA workforce, creatively expand care to the underserved, and develop a more 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.

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- A Utah program has used its PA training grant to promote interprofessional teams. The grant allowed the program to optimize its relationship with three service-learning partners, develop new partnerships with three service-learning sites, and create a model geriatric curriculum that includes didactic and clinical education.
- 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.

Recommendations on FY 2015 Funding

The Physician Assistant Education Association requests the Appropriations Committee's support in funding for Title VII health professions programs at a minimum of $266.4 million for FY 2015.This level of funding is crucial to support the nation's ability to produce and maintain highly skilled primary care practitioners, particularly those from diverse backgrounds and the military who will practice in medically underserved areas and serve vulnerable populations. We also ask for the continuation of the 15 percent allocation for PA education programs in the Primary Care cluster as mandated in the Affordable Care Act. The Accreditation Review Commission on Education for the Physician Assistant estimates that an additional 75 programs will be added by 2018. Therefore, we request an increase in funding to $12 million which will allow sufficient funding for the expanding number of PA programs expected to begin enrolling students during the next four to five years.

We thank the members of the subcommittee for their support of the health professions and look forward to your continued commitment to finding solutions to the nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's FY 2015 funding recommendation.

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Written Testimony of Mark Dunning of Massachusetts
Labor, Health and Human Services, Education and Related Agencies
Subcommittee of the House Committee on Appropriations
March 28, 2014

Parent of a 15 year old daughter with Usher Syndrome, Founder and Chairman of the Coalition for Usher Syndrome Research

My name is Mark Dunning from the state of Massachusetts. As Chairman of the Coalition for Usher Syndrome Research, I am here on behalf of the Usher syndrome community to respectfully request this committee encourage NIH to prioritize research that will eventually expand treatment options for individuals suffering from the severe hearing and vision loss related to Usher syndrome. We also respectfully request that the committee direct NIH to move expeditiously to direct additional resources to respond to any deficiencies in the funding level or the manner in which various ICs coordinate on common goals and objectives related to Usher syndrome.

Usher syndrome is the leading cause of deaf-blindness. In the United States, it is estimated that about 45,000 people have this rare genetic disorder. My fifteen year old daughter Bella is one of them. She has Usher syndrome type 1b. She was born profoundly deaf and now she is losing her vision to retinitis pigmentosa. She also suffers from the severe balance issues common in her type of Usher syndrome.

Imagine yourself as a fifteen year old girl. Adulthood stands before you. You dream of getting your driver's license, of the freedom it provides, of the limits it removes. We live in a small town. There is no public transportation. A car is the only way to get to work, to visit friends, to shop for food. But Bella's vision is too poor for driving. How will she survive?

Or imagine yourself as a sophomore in high school. You dream of college, of the freedom it provides, of the limitless career opportunities. Only hard work and desire stand between you and your dreams. Unless, like Bella, you have Usher syndrome. Then you also face the barriers of access to information. You cannot hear the professor or see the board as well as your peers. You work many times harder to get the same grades. And some trades are closed to you before you start. Can you be an architect if you are losing your vision? Can you be a salesperson if you have no hearing? Can you dare to dream of an unfettered future? Is the American dream available to you if you have Usher syndrome?

My daughter is an asset to this country. She is kind and empathetic. She puts all others before herself. She is hard working and fearless. She has been honored with a John F. Kennedy award for leadership and a StayClassy award for philanthropy. She is the type of fifteen year old we should be grooming as a future leader in the country.

But Bella has Usher syndrome. She was born profoundly deaf and she is going blind. She will fight it every step of the way, but without increased federal funding, she will eventually lose. And when Bella loses, we all lose. Kids like Bella are our future. Unless they have Usher syndrome. Then they are not, and we are all the worse for it.

People with Usher syndrome share the same range of intelligence and work ethic as any other slice of America. Yet they suffer from an 82% unemployment rate. People with Usher syndrome are born with the same emotional strength as any other American. Yet they have a suicide rate that is 2 ½ times greater than the general population. People with Usher syndrome not only have the capacity to contribute to America's future, they thirst for it. They want to be active members of society. Yet our country spends an estimated $139 billion annually in direct

and indirect costs for people with eye disorders and vision loss[1]. That doesn't even include the costs associated with hearing impairment.

In my role as the Chairman of the Coalition for Usher Syndrome Research, I have spoken with or met hundreds of people who are determined, focused, and working everyday to help themselves, their loved one, or in some cases complete strangers, figure out how to treat this syndrome. Usher genes are complex, long protein cells which require significant investment in research if we are ever to find a cure or treatment. We can't do it alone.

Through the Coalition, we have brought the Usher community and researchers together by:

- Establishing a registry of individuals with Usher syndrome which is available for research or clinical trials at no cost. Our registry currently has families from each of the 50 states and 29 countries.
- Sponsoring an International Symposium on Usher Syndrome at the Harvard Medical School in July 2014 to develop a roadmap for future research projects to bring us closer to viable clinical trials.
- Sponsoring annual family conferences, webinars and monthly conferences that provide information and support to all of those living with Usher.

With this in place, we have begun bringing brilliant researchers together who are working on developing treatments every day. Researchers like those in Oregon and Pennsylvania who are working on gene therapy treatments, one of which began clinical trials last year. Researchers in Louisiana, who have been able to rescue the hearing in mice with Usher syndrome using a drug

[1] Wittenborn, John S. & Rein, David B. "Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States." NORC at the University of Chicago. Prepared for Prevent Blindness America, Chicago, IL. June 11, 2013. http://costofvision.preventblindness.org.

therapy that holds promise for rescuing vision as well. Researchers in Iowa, California, Nebraska, Massachusetts, Florida, Texas, and many other states, who are collaborating with each other and with families through the Coalition to advance all kinds of Usher syndrome research.

But still this is not enough. We cannot help any of the tens of thousands who have Usher, or countless others that will be born in the future with this devastating genetic disorder without Federal support. There are dozens of different mutations that cause Usher syndrome, and the pace of research is slowed dramatically by the lack of researchers and funding. The infrastructure is there to find treatments, but the significant financial support is not. We are asking you to supply this last critical resource to help us find a cure.

When you review the report on categorical spending by the NIH, Usher syndrome is not even listed. Rare diseases with similar incident rates average around $50 million annually. These investments have resulted in significant discoveries for these diseases and there is reason to believe that we can see these same results or better for Usher syndrome. We do not ask that the committee throw dollars at the problem. Only that they ensure the appropriate funding is available. The researchers are there, waiting to discover what now is just a dream. All we are asking for is a chance; a chance for deaf children and adults who are going blind, a chance to see. With your help, my daughter and others like her can once again dare to dream.

I will leave you with the words of America's most famous deaf-blind person, Helen Keller. "Alone we can do so little; together we can do so much." Only together can we find a way to end deaf-blindness. I thank you on behalf of all those with Usher syndrome, their families, and most importantly to me, my daughter Bella.

Name: Michele Arnold of Bellaire Texas

Title: Volunteer legal guardian for Larry Wright who lives at

Affiliation: Richmond State Supported living Center (RSSLC) in Richmond, Texas

My request is that you prohibit the use of HHS appropriations that support deinstitutionalization activities because they evict eligible individuals with I/DD from HHS-licensed and funded homes.

I wish I could attend your hearing but my work schedule will not allow it. Here is my perspective from 16 years of spending time with the residents at RSSLC:

My ward, Larry Wright, lives happily at Richmond State Supported Living Center (RSSLC). He has two part-time jobs on campus and is proud to get there and back to his cottage in his wheelchair. He enjoys spending his wages at stores in the area or on trips around Texas with his hand-bell choir. He enjoys going to restaurants with his friends and into Houston to attend museums and events such as the rodeo.

Larry is free to visit his many friends all over campus whenever he wishes on paths designed for wheelchairs. Many of his friends swim in the campus pool and others ride horses as part of their physical therapy program. They gather Friday nights for dances in the gym and during the week at the computer lab/coffee shop.

Registered nurses give Larry his medication and when he is ill, he can stay in bed and recuperate. His dentist understands the special needs and fears of Larry and his friends; therefore, Larry participates in his oral health.

Richmond State Supported Living Center is a lively community with parents, family members, and friends coming to visit plus volunteers who live in the area coming to spend time with our loved ones. It's a healthy, professionally run community, and I hope that families who need such holistic services will be allowed to have their loved ones make a home there.

My reason for writing is to tell you some things you will never hear from the people who wish to close large, state-run facilities down; namely, group homes for people with intellectual and developmental disabilities are abusive for the following reasons:

1. Group home customers in Texas must go to day hab five days a week whether they are sick or healthy. That means that customers with fever, vomiting, diarrhea, etc. will be forced into a van and driven -- sometimes at quite a distance -- to day hab. When it's convenient for a nurse to visit, she will. The sick must lie among the healthy for the entire day, sometimes on beds with no sheets or on a pile of blankets on the floor.

2. The social life for group home customers is restricted to other customers and staff most days of the year.

3. Group home customers are locked in their houses every night after day hab and most weekends, with the exception of trips to places like dollar stores and public parks. Some houses are not required to be ADA compliant.

4. Most customers are not allowed to go to church because there's no staff to take them.

5. Neighbors of group homes feel sorry for the customers in their midst because they see the restrictive conditions, but neighbors are also angry that a business is being run in their neighborhood.

Elected officials need to visit group home businesses and the non-profit communities run by the states -- with no advance notice – to understand how different the quality of life is.

Texas media rarely reports on group home abuses and deaths. This story from 2008 illustrates the poor medical care that group home customers receive:

Deadly house fire may have been arson Friday, September 5, 2008

By Andy Cerota 666-0713

HOUSTON (KTRK) -- One woman is dead, and another hospitalized after fire tore through their home late Thursday night, and investigators believe it was not an accident.

Firefighters say flames were shooting out of the roof of the house on Beretta Court at Quail Hills when they arrived. That home was being used as an assisted living center for disabled adults.

Arson investigators spent the afternoon at the scene of Thursday night's fatal house hire. It's a fire they are now calling suspicious. Flame swept through the single story home so quickly, that by the time firefighters put it out, there was nothing left but charred remains.

"It's a tragedy," said neighbor Prince Williams. "It's real bad. I pray for their families because everybody needs prayer at this time."

Neighbors say the home that burned is a community based group home for people with special needs. Four young adults with mental and physical disabilities lived there.

"I know the so-called caregivers. They came in shifts, sometimes some come three in the afternoon, some come later or early in the morning," recalled neighbor Robert Evans.

Of the four who lived here, firefighters had to rescue two of the women from the burning home. One of them later died.

While the cause of the fire is still investigation, a neighbor told us one of the special needs residents admitted to setting it.

"She said that she set the fire with a lighter," neighbor Stephanie Pullins told Eyewitness News. "She said she got mad at them at them because they didn't call the nurse. Because she had hurt her foot and she wanted to go to the doctor and she didn't care about going to jail. And I asked her how did she set the fire and she said with a lighter."

The front of the house suffered a great deal of damage. Exactly where the fire began is still under investigation.

**

These are some of the organizations that do not deserve taxpayer money because they have antiquated ideas about "institutions" and are prejudiced against state-run campuses: National Council on Disability (NCD), Administration on Intellectual and Developmental Disabilities (AIDD), DD Act programs (state councils on developmental disabilities, P&A programs).

Thank you for asking the public for their perspectives.

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 FISCAL YEAR (FY) 2015 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 HOUSE COMMITTEE ON APPROPRIATIONS
March 27, 2014

EXECUTIVE SUMMARY

NAEVR requests Fiscal Year (FY) 2015 NIH funding of $32 billion, which would fully restore the $1.7 billion FY2013 sequester cut partially restored in FY2014 and enable an inflationary increase–the NIH has lost 22 percent of its purchasing power since FY2003, in terms of constant dollars–and provide for modest growth. This request improves on the President's proposal to increase NIH funding by only $200 million over FY2014 and which also increases the Program Evaluation Transfer to 3 percent, effectively reducing NIH's increase by $150 million. FY2015 NIH funding of $32 billion is an important step toward consistent and sustained funding increases which are necessary to build upon past investment that has created an unprecedented scientific opportunity in biomedical research.

NAEVR requests National Eye Institute (NEI) funding at $730 million. The President's budget proposes a minimal NEI increase of $0.9 million or 0.15 percent, based on its FY2014 operational net of $675 million–not its $682 million appropriation. This is unacceptable since NEI has lost 25 percent of its purchasing power since FY2003, and the FY2013 sequester has already resulted in NEI awarding 30 fewer grants–any one of which may have held the promise to save sight and restore vision.

AS NEI'S BUDGET DECREASES, THE INCIDENCE OF EYE DISEASE AND VISION IMPAIRMENT INCREASES, AS DOES THE ASSOCIATED COST ESTIMATED AT $139 BILLION ANNUALLY IN THE UNITED STATES

Although the FY2013 sequester cut reduced NEI's budget by $36 million to $662 million, $20 million of that was restored in FY2014 through an appropriation of $682 million. In each year, however, NEI's appropriation was reduced even further by $5.6 million and $6.9 million to operational nets of $657 million and $674 million, respectively, due to the transfer back to the NIH Office of AIDS Research (OAR) for funding of the dissolved NEI-sponsored Ocular Complications of AIDS studies. Although OAR's funding to NEI was not committed into perpetuity, its return to NIH Central effectively reflects a cut in NEI funding and results in a new baseline upon which future funding will be based. For example, the President's FY2015 budget request bases its 0.15 percent NEI increase on the FY2014 operational net of $674 million, which results in just a $0.9 million increase in NEI funding to $675 million. The funding nets described above are well below NEI's highest appropriation–that of $707 million in FY2010 (prior to addition of American Recovery and Reinvestment Act (ARRA) funding. Unfortunately, as NEI funding has decreased, the challenges it faces have grown, due to dramatic increases in the incidence and cost of vision impairment and eye disease.

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 age-related macular degeneration (AMD), glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. Much of this is being driven by the aging of the population, for example, the "Silver Tsunami" of the 78 million baby

boomers who will turn age 65 this decade and experience the greatest risk for eye disease. Other demographic changes are also contributing to NEI's challenges, for example, African Americans and Hispanics which increasingly account for a larger share of the U.S. population and who experience a disproportionately greater prevalence of eye disease. Vision loss can also be a co-morbid condition of chronic disease, such as diabetes, which is at epidemic levels due to the increased incidence of obesity.

In June 2013, Prevent Blindness America, in conjunction with the National Opinion Research Center at the University of Chicago, released updated estimates of the cost of vision disorders. NORC estimates the annual costs of vision disorders at $139 billion, inclusive of direct and indirect costs. Most importantly, the direct medical costs associated with vision disorders are the fifth highest–only less than heart disease, cancers, emotional disorders, and pulmonary conditions.

NEI's FY2014 operational net funding of $674 million, as well as the President's FY2015 proposed funding of $675 million, are each less than 0.5 percent of this $139 billion annual vision disorder cost burden. The U.S. is spending only $2.10 per-person, per-year for vision research at the NEI, while NORC estimates that the cost of treating low vision and blindness is $6,690 per-person, per-year.

In 2009, Congress spoke volumes in passing S. Res 209 and H. Res. 366, which designated 2010-2020 as *The Decade of Vision* and recognized NEI's 40th anniversary

as the lead institute in funding research to save sight and restore vision. With the FY2015 LHHS spending bill, Congress can act upon its past resolutions regarding vision and ensure that NEI is adequately funded to meet these challenges.

$730 MILLION FY2015 FUNDING ENABLES NEI TO PURSUE ITS PRIMARY "AUDACIOUS GOAL" OF RESTORING VISION

NEI has lost 25 percent of its purchasing power since FY2003. The FY2013 sequester cut resulted in NEI awarding 30 fewer grants, and the President's FY2015 proposal would result in 23 fewer awards. Any one of those missed funding opportunities could have held the promise to save sight and restore vision–goals that would have seemed unattainable just a few short years ago.

The NEI has long been a leader in biomedical research. As NIH Director Francis Collins, M.D., Ph.D. stated in February 2013:

> "It's often, it seems to me, that vision research is a couple of steps in front of things that are happening in biomedical research. It's clear that vision research has played a disproportionately large share in scientific breakthroughs."

Dr. Collins made his comments at NEI's *Audacious Goals Development* meeting, where more than 200 attendees reflecting every sector of the vision community, including government scientists and regulators from various disciplines, discussed topics built around the ten winning submissions from a pool of nearly 500 entries selected through NEI's *Audacious Goals in Vision Research and Blindness Rehabilitation Challenge.* This initiative, conducted by NEI with its National Advisory Eye Council (NAEC) and through *The America Competes Act,* yielded such ideas as restoring light sensitivity to the blind

through gene-based therapies and visual prosthetics, pinpoint correction of defective genes, and growing healthy tissue from stem cells for ocular tissue transplants.

In consultation with the NAEC, the NEI converged on its primary Audacious Goal for vision research: **To Regenerate Neurons and Neuronal Connections in the Eye and Visual System."** In terms of what this would mean for some common eye diseases:

- For AMD, it could mean the development of light-sensitive photoreceptor cells and their placement into the retina of individuals who are blind from the disease.
- For glaucoma, it could mean the development of new retinal ganglion cells which would then be transplanted into the retina of individuals with vision loss.

As NEI Director Paul Sieving, M.D., Ph.D. stated in February 2014:

> "The goals are bold but achievable. They are beyond what medicine currently can do. We are planning for a 10-12-15 year effort to reach these endpoints. Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases."

These are ambitious goals that require increased–not decreased–funding. Our nation's investment in vision health is an investment in its overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals maintain their independence, and generally improve quality of life, since vision loss is associated with increased depression and accelerated mortality.

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 55 professional ophthalmology and optometry, patient and consumer, and industry organizations involved in eye research.

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EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

MARCH 28, 2014

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 Jennifer A. Buda and I serve as a member of the Board of Helen Keller International (HKI). I am requesting that this Subcommittee recommend that the United States Department of Education support programs that provide vision care for children from economically disadvantaged families in fiscal year 2015.

It is HKI's hope that with the continued support of the Department of Education and private donors, we can deliver free 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 United States. More commonly known as nearsightedness, farsightedness and astigmatism, refractive error affects one in four children and adolescents nationwide. 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. This is especially tragic since most cases of poor vision are due to refractive error and are easily corrected.

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. 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. ChildSight® helps students directly by going into the schools to conduct vision screenings, identifying children with refractive error and providing prescription eyeglasses to address this need, all free of charge. In so doing, ChildSight® "brings education into focus™" for children who would otherwise be left with untreated vision problems – and lost opportunities.

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 on-site 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. ChildSight® provides direct access to vision screening and refraction by a licensed optometrist who prescribes the necessary lenses for each child.

ChildSight® goes 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.

POSITIVE RESULTS

Since its inception, ChildSight® has screened over 1.6 million children and delivered over 225,000 pairs free eyeglasses to children in need, with support from this Subcommittee, the Department of Education and private donations. 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 improvement in grades, self-confidence and self-perception as reported by the teachers.

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 our partner physicians, educators, community activists and business people in each of our local sites. 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 of 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 foundations including the Community Foundation for Greater New Haven, Daniels Fund, Lavelle Fund for the Blind, Mt. Sinai Health Care Foundation, New York Community Trust, Children's Aid Society, Rose Hills Foundation, Victoria Foundation, Healthcare Foundation of New Jersey and Reader's Digest Partners for Sight Foundation.

Local health care professionals, such as optometrists, pediatric ophthalmologists and opticians, at our program sites are members of the ChildSight® team who help us meet the vision care needs of the students we serve. ChildSight® contracts with ophthalmic clinics and optical shops selected according to their strong professional credentials. The services of these community professionals are either donated or provided at a reduced, reasonable rates.

CONCLUSION

ChildSight® provides an invaluable – and often life changing – service to local youth in a pragmatic and cost-effective manner. I ask this Subcommittee to recommend in its fiscal year

2015 Committee report that the United States Department of Education support programs that provide vision care for children from economically disadvantaged families. These Department of Education funds will support ongoing programs and will provide vision screening and prescription eyeglasses for children.

As our founding board member Helen Keller said: *Alone we can do so little; together we can do so much.*

STATEMENT ON AMYLOIDOSIS

BY

ANN D. PEEL

PRIVATE CITIZEN, BETHESDA, MARYLAND

THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,

EDUCATION AND RELATED AGENCIES

COMMITTEE ON APPROPRIATIONS

U.S. HOUSE OF REPRESENTATIVES

MARCH 28, 2014

Mr. Chairman,

Amyloidosis is a rare, often fatal disease. I ask that you include language in the Committee's report for fiscal year 2015 urging the National Institutes of Health and other health agencies to fund research for amyloidosis and to increase awareness of the disease.

I have been treated for amyloidosis and want to use my experience to help others.

Amyloidosis can cause heart, kidney, or liver failure and severe neurologic problems. Left untreated, the average survival is only about 15 months from the time of diagnosis. Amyloidosis can literally kill people before they even know that they have the disease.

Progress has been made in research and treatment for various types of amyloidosis, but no one has been able to determine the root cause of the disease or an effective low-risk treatment. Only limited research is currently being funded. Much, much more needs to be done.

The small numbers of patients with amyloidosis who are able to obtain treatment face challenges that can include high dose chemotherapy and stem cell replacement or organ transplantation. Thousands of people die because they were diagnosed too late to obtain effective treatment. Thousands of others die never knowing they had amyloidosis

Amyloidosis is vastly under-diagnosed. This is especially the case in the African-American community.

AMYLOIDOSIS

Amyloidosis occurs when proteins are deposited in 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. I have been treated for primary amyloidosis, a blood or bone marrow disorder.

In addition to primary amyloidosis, there are also thousands of cases of inherited (familial) and age-related amyloidosis. It was not until the early 1980s that the most common familial type of amyloidosis was found to be caused by mutations in a protein made in the liver. This is the form of amyloidosis that may be present in up to 3% of African-Americans.

Older Americans, usually white men, are susceptible to heart disease due to amyloidosis formed from the non-mutated form of the same protein. Another type of amyloidosis, secondary or reactive amyloidosis, occurs in patients with chronic infections or inflammatory diseases.

It was not until the 1980s that research identified the most common amyloid proteins and rationales for treatment were being discussed. The first clinical trial using oral chemotherapy for primary amyloidosis was begun in the late 1980s, and high dose chemotherapy with stem cell transplantation was developed in 1994.

The first liver transplant in the United States for familial amyloidosis was performed in 1992.

All of these types of amyloidosis, left undiagnosed or untreated, are fatal. There is no explanation for how or why amyloidosis develops and there is no known reliable cure.

AMYLOIDOSIS TREATMENT

The Amyloidosis Center at Boston University School of Medicine and Boston Medical Center, and other centers for amyloidosis treatment, have found that high dose intravenous chemotherapy followed by stem cell replacement is an effective treatment in selected patients with primary amyloidosis. 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 remission rate and long-term survival dramatically.

However, more research needs to be done to provide less risky forms of treatment.

RESEARCH, DIAGNOSIS AND TREATMENT

Researchers are moving forward with limited funding to develop targeted treatments that will specifically attack the amyloid proteins. 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 diagnosis and 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, particularly the Office of Rare Diseases, participates in meetings and symposiums and works closely with organizations doing research and outreach on amyloidosis.
- Research supported by the National Institute of Neurologic Disorders and Stroke at NIH and the Office of Orphan Products Development at the Food and Drug Administration has led to successful repurposing of a generic drug that markedly slows progression of familial amyloidosis. This represents the first readily available drug treatment for this disease. There is also hope, with increased funding for research, to expand the range of treatment to other categories of amyloidosis.
- There has been increased basic and clinical research at the Boston University Amyloidosis Center: models of disease have been developed; factors that cause protein misfolding are being identified; and new clinical trials are underway. A study of the age-related form of amyloid heart disease will provide natural history data critical for the design of future clinical trials. The National Institute of Aging is supporting this work.

- Federal funding for research, equipment and treatment has been an important element in progress to date. Further funding is essential to speed the pace of discovery for basic and clinical research.

REQUEST FOR FISCAL YEAR 2015

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.

The United States Congress and the Executive branch working together are essential to finding a cure for and alerting people to this terrible disease.

Help me turn what has been my own life-threatening experience into hope for others.

Thank you for your consideration.

Testimony of David Hawkins
Director of Public Policy and Research
National Association for College Admission Counseling (NACAC)
Labor-Health and Human Services-Education Subcommittee
House Appropriations Committee
March 28, 2014

Chairman Kingston, Ranking Member DeLauro and Members of the Subcommittee, on behalf of the National Association for College Admission Counseling (NACAC), thank you for the opportunity to submit testimony regarding the Fiscal Year 2015 Labor-Health and Human Services-Education appropriations bill. NACAC urges at least level funding for the Department of Education's GEAR UP and the TRIO programs and the Elementary and Secondary School Counseling Program. It also calls for adequate funding for the Department of Education's financial aid programs.

Founded in 1937, NACAC is an organization of more than 13,000 professionals from around the world dedicated to serving students as they make choices about pursuing postsecondary education. NACAC is committed to maintaining high standards that foster ethical and social responsibility among those involved in the transition process, as outlined in the NACAC Statement of Principles of Good Practices (SPGP), which can be found on our website (www.nacacnet.org). Our members include school counselors, college admissions officers, independent educational consultants, community-based organizations, counselor educators, among others. Regardless of where we hang our hat, our goals are the same: to help students navigate the admissions process and enroll in a college or university that meets his or her needs.

As you well know, the importance of a college degree is increasing each day. During the many hearings you will hold on the FY15 budget, I am sure that you will hear dozens of statistics. I

would like to remind you of a couple that are, arguably, the most important to families in your Districts and the future of our nation:

- According to the Department of Education, ninety percent of the fastest growing jobs in America require a postsecondary credential or training, yet only 41 percent, or 11.5 million, of 18-24 year olds were enrolled in college in 2008 according to the American Association of State Colleges and Universities. To put that in perspective, it is estimated that by 2018, the United States economy will face a shortage of at least 3 million post-secondary degrees;
- The Georgetown Center on Education and the Workforce reports that graduates who earn a bachelor's degree or higher can be expected to earn 74 percent more over a lifetime than those who only complete high schools; and
- The Alliance for Excellent Education reported that the nearly 1.2 million high school dropouts from the class of 2008 represent a $319 billion loss to the economy in lifetime earnings. It went on to say that reducing the dropout rate by 50 percent for a single high school class would result in home sales totaling as much as $10.5 billion and auto sales totaling $340 million.

In short, helping students graduate high school and attend college, either at a 2 year or 4 year institution, is good for families and our economy. Based on NACAC's research and collaborations with thirty other organizations in the Pathways to College Network, we have identified two major policy areas to improve college access: quality counseling and need-based financial aid.

Access to quality counseling is a crucial component of students' post-secondary educational planning and enrollment. High school students have many options available to them; but there are also a lot of question students must answer as they decide which college to attend; the most critical being what type of college is best for him/her and how to pay for it. Guidance counselors are crucial to helping students answer these questions and help student make smart decisions about their future. Therefore, we urge the Subcommittee to at least maintain funding for GEAR UP and TRIO in FY2015 as the programs currently receives. These programs provide college counseling and early awareness services that are invaluable to students from low-income families, many of whom are the first in their families to consider attending college.

In addition, we urge the Subcommittee to at least maintain funding for the Elementary and Secondary School Counseling Program (ESSCP) in FY2015 as it received in FY14 so that funds are available to secondary schools. The ESSCP is the *only* federal program devoted to creating and expanding counseling programs in schools. In addition to providing critical support for with social, emotional, and behavioral issues, counselors provide students with college and career counseling as they transition into adulthood. As part of the No Child Left Behind Act, Congress expanded the ESSCP to include secondary school activities. However, due to the program's statutory funding trigger, secondary schools cannot benefit unless total funding exceeds $40 million, with that base amount reserved for elementary schools. This funding trigger has been met each year since FY 2008, which has allowed middle and high schools to apply for grants.

Currently ratios of school counselors to students far exceed the recommendations of the professional organizations that represent them. The recommended ration is 250 students to 1

counselor; in Georgia, the ratio is 471 to 1 and in Connecticut the ratio is 518 to 1. Grants awarded through ESSCP help reduce these ratios, ensuring that students receive high quality counseling when they need it. We urge the Subcommittee to at least maintain the level of funding for ESSCP in FY15.

Another important component of college access is affordability. According to the Department of Education, for the 2010–11 academic year, annual prices for undergraduate tuition, room, and board was approximately $13,600 at public institutions and $36,300 at private institutions. Between 1999–2000 and 2010–11, prices for undergraduate tuition, room, and board at public institutions rose 42 percent, and prices at private institutions rose 31 percent, after adjustment for inflation.

Unfortunately, the steadily increasing costs coupled with the struggling economy are making it difficult for many students to attend college. Federal financial aid programs are the most successful aid programs available to students. These programs provide students with the means to a degree without saddling them with massive debt which often results from private loans.

Therefore, we strongly urge you to at least maintain investment in the Pell Grant so that the maximum award keeps pace with the cost of postsecondary education and to avoid a shortfall. We also encourage the Subcommittee to provide funding for other need-based aid programs, including Supplemental Educational Opportunity Grants (SEOG) and Work Study, to help make college more affordable to students.

These programs are key to making college affordable for students. As you know, businesses throughout the country are seeking educated, highly skilled workers. Unfortunately, the demand for these workers outstrips supply and this trend will only increase if students are unable to afford college. NACAC recognizes that our country faces incredible fiscal challenges; however, we strongly believe that these programs are critical to preparing our students to enter the workforce, leading to a more productive workforce, increase tax revenues, all of which will help address our nation's fiscal problems.

Again, thank you for the opportunity to provide written testify to the House Appropriations Committee. I am happy to answer any questions you might have. I can be reached at 703.299.6809 or dhawkins@nacacnet.org.

Public Witness Testimony of Jill Kagan, Chair, National Respite Coalition
For the House Subcommittee on Labor, HHS and Education Appropriations
In support of funding for the Lifespan Respite Care Program, Administration for Community Living (ACL)/Administration on Aging (AoA), US Dept. of Health and Human Services
March 26, 2014

Mr. Chairman, I am Jill Kagan, Chair of the National Respite Coalition (NRC), a network of state respite coalitions, respite providers, family caregivers, national, state and local organizations that support respite. The NRC also facilitates the Lifespan Respite Task Force, a coalition of over 100 national, state and local groups. The NRC is **requesting that the Subcommittee include $2.5 million for the Lifespan Respite Care Program in the FY 2015 Labor, HHS, and Education Appropriations bill or designate this amount from the Prevention and Public Health Fund as recommended in the President's FY 15 budget.** This will enable:

- State replication of Lifespan Respite best practices to allow family caregivers, regardless of the care recipient's age or disability, to access affordable respite;
- Expansion of respite quality and capacity, including recruitment/training of respite workers, building faith-based and volunteer respite, and encouraging informal supports; and
- Greater consumer direction by providing family caregivers with training and information.

Who Needs Respite? A 2012 Pew Research Center survey found that four in ten adults in the U.S. are caring for an adult or child with significant health issues, up from 30% in 2010 *(Fox, S, et al, 2013)*. The estimated economic value of unpaid contributions of family caregivers is approximately $450 billion -- more than total Medicaid spending, including both federal and state spending for health care and long-term services and supports (*AARP Public Policy Institute, 2011)*. Caregiver support is a lifespan issue with the **majority** of family caregivers caring for someone **under age 75 (56%)** *(National Alliance for Caregiving (NAC), 2009)*.

National, State and local surveys have shown respite to be the most frequently requested service of the nation's family caregivers *(The Arc, 2011; National Family Caregivers Association, 2011*). ***Other than financial assistance for caregiving through direct vouchers payments or tax credits, respite is the number one national policy related to service delivery that family caregivers prefer (NAC and AARP, 2009).*** Yet, **nearly 90% of family caregivers across the lifespan are not receiving respite services at all.**

Respite Barriers and the Effect on Family Caregivers. Barriers to accessing respite include fragmented and narrowly targeted services, cost, and the lack of information about respite or how to find or choose a provider. A critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need. Lifespan Respite is designed to help states eliminate barriers through improved coordination and capacity building.

While most families want to care for family members at home, research shows that family caregivers are at risk for serious emotional, mental, and physical health problems *(Family Caregiver Alliance, 2006)*. Parents of children with special health care needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing (TD) children *(McBean, A, et al, 2013)*. When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of abuse from caregivers among care recipients with significant needs increases when caregivers themselves are depressed or in poor health *(American Psychological Association, nd)*.

Supports that would ease family caregiver stress, most importantly respite, are too often out of reach or completely unavailable. Restrictive eligibility criteria preclude many families

from receiving services. Children with disabilities age out of the system when they turn 21 and lose services, such as respite. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found the vast majority of caregivers report physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%); 1 out of 5 families (20%) report that someone in the family quit their job to provide care; and more than 75% of family caregivers could not find respite services *(The Arc, 2011).* Respite may not exist at all for those with Alzheimer's, with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions.

Respite Benefits Families and is Cost Saving. Respite has been shown to help reduce stress and improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, minimizes precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A study of parents of children with autism found that respite was associated with reduced stress and improved marital quality *(Harper, Amber, et al, 2013).* A US Dept of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry *(Spillman and Long, USDHHS, 2007).* In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75% *(NAC, 2012).*

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for one person with Alzheimer's can save Medicaid and other government programs thousands of dollars. Researchers at the University of Pennsylvania studied the records of

28,000 children with autism enrolled in Medicaid in 2004. They concluded that for every $1,000 states spent on respite, there was an 8% drop in the odds of hospitalization *(Mandell, David S., et al, 2012)*. In the private sector, U.S. businesses lose from $17.1 to $33.6 billion per year in lost productivity of family caregivers *(MetLife Mature Market Institute, 2006)*. Higher absenteeism among working caregivers costs the U.S. economy an estimated $25.2 billion annually *(Witters, D., 2011)*. Respite for working family caregivers could improve job performance, saving employers billions.

Lifespan Respite Care Program Helps. The federal Lifespan Respite program, administered by the Administration for Community Living (ACL), Administration on Aging (AoA) in HHS, provides competitive grants to eligible state agencies. Congress appropriated $2.5 million each year from FY09 - FY12 and slightly less in FY13 and FY14. Since 2009, 32 states and DC have received Lifespan Respite Grants. States are 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. Lifespan Respite, defined as a coordinated system of community-based respite services, helps states maximize use of limited resources across age and disability groups and deliver services more efficiently.

How is Lifespan Respite Program Making a Difference? With limited funds, Lifespan Respite grantees are engaged in innovative activities such as:

- expanding volunteer networks of providers in TN and RI.
- engaging the faith community in helping to provide respite, especially in rural areas, in SC, AL and PA.

- partnering with the Money Follows the Person program to develop family caregiver peer-to-peer support and respite in NC and training respite workers in OH.

Partnerships between state agencies are changing the landscape. The AZ Lifespan Respite program housed in Division of Aging and Adult Services partnered with the state's Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the state's Federal Transit Administration's to develop mobile respite to serve isolated rural areas of the state. States are building respite registries and "no wrong door systems" to help family caregivers access respite and funding sources. OK, AL, NV, TN and others are using Lifespan Respite grants to implement participant-directed respite using vouchers so that family caregivers have control over the respite they select. Funding must be maintained to help sustain these innovative state efforts. States are developing comprehensive sustainability plans, but without federal support, many of the grantees will be cut off before they have had a chance to have a lasting impact.

With tens of millions of families affected, **caregiving is a public health issue requiring an immediate proven preventive response**, such as respite. We urge you to include at least $2.5 million in the FY 15 Labor, HHS, and Education appropriations bill or designate this amount in the Prevention and Public Health Fund. This will allow Lifespan Respite Programs to be replicated and sustained. Families, with access to respite, will be able to maintain their own health and well-being and continue to play the significant role that they are fulfilling today.

Complete references available upon request. Prepared by Jill Kagan, Chair, National Respite Coalition, 4016 Oxford St, Annandale, VA, 22003; 703-256-2084; jkagan@archrespite.org ; www.archrespite.org.

Statement of the
NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS
1100 17th St. NW, 7th Floor
Washington, DC 20036

Submitted for the record to the Subcommittee on Labor, Health and Human Services and Education, Committee on Appropriations
United States House of Representatives

FY 2015 Appropriations for Programs at the Department of Health and Human Services

Contact: *Eli Briggs, NACCHO Government Affairs Director*
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The National Association of County and City Health Officials (NACCHO) is the voice of the 2,800 local health departments across the country. City, county, metropolitan, district, and tribal health departments work every day to ensure the safety of the water we drink, the food we eat, and the air we breathe.

On behalf of local health departments, NACCHO submits the following requests:

Prevention and Public Health Fund (HHS)

In FY2015, NACCHO requests $1 billion for the Prevention and Public Health Fund (PPHF), a dedicated federal investment in programs that prevent disease at the community level. NACCHO wishes to thank Congress for allocating the PPHF in FY2014 and setting specific funding levels to support the prevention of disease and promotion of health in communities across the nation.

CDC Public Health Emergency Preparedness

NACCHO urges the Subcommittee to provide $675 million for the Public Health Emergency Preparedness (PHEP) grant program in FY2015. PHEP protects communities by strengthening local and state public health department capacity to effectively respond to public health

emergencies including terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and radiological emergencies. These grants have been cut more than 30 percent since FY2007 with more than 55 percent of local health departments relying solely on federal funds for emergency preparedness activities. It is important for Congress to understand the extent to which federal resources are getting to the local level, therefore NACCHO urges inclusion of language asking CDC to provide information on how much of the state PHEP grants are being allocated to local health departments and on what basis or formula each state is determining such allocations, including the method through which states reach statutorily-required concurrence with local health departments.

Assistant Secretary for Preparedness and Response (ASPR)

NACCHO urges the Subcommittee to fund the Hospital Preparedness Program (HPP) at $300 million in FY2015 and restore some of the $104 million cut from the program in FY2014. HPP provides grant funding to states and four directly funded cities that in turn fund local health departments, healthcare facilities, and other partners to build capabilities and capacities that strengthen the preparedness, response, recovery, and resilience of the public health and healthcare system. HPP supports health department preparedness coordinators to organize coalitions of public health and healthcare providers to plan and prepare for public health emergencies, including medical surge following terrorist attacks, mass casualty incidents, an influenza pandemic or other infectious disease outbreak. NACCHO is concerned that the 35% cut to HPP in FY2014 will erode medical system preparedness, making communities across the country more vulnerable. NACCHO urges Congress to request information from ASPR on how state HPP funding is distributed at the local level, including how much is being allocated to local

health departments and on what basis or formula each state making such allocations. This information should be publicly available.

CDC Section 317 Immunization Program

NACCHO urges the Subcommittee to provide $650 million for the Section 317 Immunization Program in FY2015. The Section 317 Immunization Program provides funds to 50 states, six large cities and eight territories for vaccine purchase for at-need populations and immunization program operations, including support for implementing immunization billing systems at public health clinics to sustain high levels of vaccine coverage. NACCHO supports directing $8 million of the funding, as proposed in the President's Budget, to continue projects to facilitate billing by health departments of public and private insurance for covered immunization services.

CDC Chronic Disease Prevention

Partnerships to Improve Community Health (Community Prevention Grants): NACCHO urges the Subcommittee to provide $100 million to support continuation of the Partnerships to Improve Community Health program in FY2015. These grants provide resources for local communities to implement evidence-based strategies to address heart attacks, strokes, cancer, diabetes, and other chronic diseases which contribute to the soaring cost of health care. Local health departments lead efforts to reduce tobacco use, increase physical activity and expand access to nutrition in order to reduce costly chronic diseases like heart disease and diabetes. While the FY2014 funds have not yet been disseminated, NACCHO has recommended to CDC that these funds will have the greatest impact by reaching local health departments either directly or through sub-grants. NACCHO urges Congress to encourage CDC to conduct a comprehensive national evaluation of the program to build the understanding of and evidence base for community-based chronic disease prevention. The evaluation should include

recommendations for national qualitative and quantitative standards for quality preventive services and a report of how much of the funding was granted to the local level and to which eligible entities.

Heart Disease and Stroke: NACCHO urges the Subcommittee to continue to support Heart Disease and Stroke Prevention at $130 million in FY2015. In FY2014, Congress provided a $76 million increase for heart disease and stroke prevention and urged CDC to ensure that some portion of the increase in funding is sub-granted to the local level. The risk factors of obesity and smoking must be addressed at the community level to combat this disease. NACCHO has urged CDC to provide funds through this program to all states and to sub-grant a ***majority*** of the FY2014 increase in funding to local health departments who are experts on community needs and prevention interventions in the area of heart disease and stroke.

Diabetes Prevention and Control: NACCHO urges the Subcommittee to continue to support Diabetes Prevention at $150 million in FY2015. In FY2014, Congress provided a $76 million increase for diabetes prevention and urged CDC to ensure that some portion of the increase in funding is sub-granted to the local level. Because evidence-based disease self-management programs are effective at improving the health status of individuals diagnosed with diabetes, greater emphasis must be placed on enhancing the reach of these community level interventions. NACCHO has urged CDC to ensure that a ***majority*** of the FY2014 increase in funding is sub-granted to local health departments.

CDC Preventive Health and Health Services Block Grant

In FY2015, NACCHO urges the Subcommittee to continue to support the Preventive Health and Health Services (PHHS) Block Grant at $160 million. This program is a vital source of funding for state and local health departments. This unique funding gives states the autonomy and

flexibility to address state problems and provide similar support to local communities, while still being held accountable for demonstrating the local, state, and national impact of this investment. NACCHO urges Congress to encourage CDC to enhance reporting and accountability for the PHHS Block Grant including providing capacity building to states for core public health capacities that may not be supported through other CDC categorical funding streams. These core capacities could include core laboratory, surveillance, information exchange systems, health information technology, billing capacity, performance management, quality improvement and systems strengthening, public health accreditation preparation, and implementation of evidence-based practices that drive improved service delivery and better health outcomes. In order to make sure that funding supports the needs of local communities, local health departments should be full partners in developing state plans. CDC should also require states to report the funding allocation used to subgrant funds to local health departments.

CDC Food Safety

NACCHO urges the Subcommittee to support CDC's Food Safety Program at $54 million in FY2015. Local and state health departments are an essential part of the process that ensures that food is safe to eat at home, at community events, in restaurants, and in schools. Continued funding is needed to advance implementation of the Food Safety Modernization Act by enhancing and integrating disease surveillance, improving outbreak and response timeliness and helping address deficits in local capacity to prevent and stop illness.

As the Subcommittee drafts the FY2015 Labor-HHS-Education Appropriations bill, NACCHO urges consideration of these recommendations for programs that protect the public's health and safety.

Testimony of Elizabeth J. Kovacs, Ph.D., on behalf of
The American Association of Immunologists (AAI),
Submitted to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies,
Regarding the Fiscal Year (FY) 2015 Budget for the National Institutes of Health
March 27, 2014

[Elizabeth J. Kovacs, Ph.D., (708) 327-2477; ekovacs@luc.edu]

The American Association of Immunologists (AAI), the world's largest professional society of research scientists and physicians who study the immune system, respectfully submits this testimony regarding fiscal year (FY) 2015 appropriations for the National Institutes of Health (NIH). ***AAI recommends an appropriation of at least $32 billion for NIH for FY 2015*** to support important ongoing research, fund a reasonable number of outstanding new grant applications, and restore NIH funding to a level that can sustain a robust and dynamic biomedical research enterprise in the United States.

NIH's Crucial Role in Advancing Biomedical Research

NIH is essential to the advancement of biomedical research in the United States, where virtually all biomedical scientists rely on NIH leadership and funding.[1] Academic scientists, many of whom conduct research while teaching the next generation of doctors and scientists, depend on NIH grants to support their research at universities, colleges and research institutions all around the country. NIH intramural scientists require funding to do their own research as well as collaborate with their private sector colleagues.[2] And scientists employed by industry, who generally do not receive NIH grants or awards, depend on NIH-funded scientific discoveries to develop products that bring research to the bedside. A strong NIH budget, therefore, is essential to all sectors of the U.S. biomedical research enterprise, and has enabled NIH to remain the key international leader influencing biomedical research around the globe.

NIH Budget Woes Slow Research and Threaten U.S. Preeminence

The slow growth of the NIH budget in recent years, exacerbated by the impact of biomedical research inflation,[3] has significantly reduced NIH's purchasing power, and in turn, the purchasing power of its

grantees. According to the Congressional Research Service (CRS),"[i]n constant 2003 dollars, FY2014 funding is 22% lower than the FY2003 level."[4] *How many avenues of research have not been followed because of this reduction? How many potential treatments and cures have been delayed or not discovered?* These are questions that cannot be answered definitively, but we do know that NIH budget reductions have already caused real and lasting damage: the loss of grant funding, even among the most highly qualified scientists; the closure of labs; the termination or interruption of important research; and the emigration of talented scientists to other countries. And we do know that too many scientists are spending too much time in a constant chase for funding, rather than conducting research and mentoring the nation's future researchers, inventors and innovators. These budget woes threaten America's preeminence in advancing basic biomedical research, discovering urgently needed treatments and cures, and "growing" brilliant young scientists.

Research on the Immune System: Essential to our Health, Crucial to our Future

The immune system is the body's primary defense against viruses, bacteria, and parasites that cause disease in millions of people every year. When the immune system is operating properly, it provides powerful protection against a wide variety of illnesses, including cancer, Alzheimer's disease, and cardiovascular disease. The immune system can, however, perform poorly, leaving the body vulnerable to infections, including influenza, HIV/AIDS, tuberculosis, malaria, and the common cold. It can also become overactive, damaging normal organs and tissues, and causing autoimmune diseases, such as allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes. Research scientists and clinicians are working to harness this powerful system to protect people and animals from infectious diseases, cancer, and many other illnesses, and to protect against natural or man-made infectious organisms (including plague, smallpox and anthrax) that could be used for bioterrorism.[5]

Recent Immunological Advances and Their Promise for Tomorrow

1. Cancer Immunotherapies: Offering Hope of Conquering Cancer

NIH-funded scientists recently identified inhibitory receptors which suppress immune cell activation.

Blocking these receptors can allow the immune system to destroy tumor cells.[6] Today, therapeutics targeted against inhibitory receptors like CTLA4 are undergoing rigorous clinical trials against a variety of cancers. The success rates for these therapies have been astounding and unprecedented: for example, rates of tumor regression in patients with metastatic melanoma have increased from ~10% to ~50%.[7] With this level of success, immunotherapy is one of the most exciting and promising areas of cancer treatment.

2. ***Early Antiretroviral Therapy: Eliminating HIV, Ending AIDS?***

NIH-funded researchers have discovered that early administration of antiviral medication, known as anti-retroviral therapy (ART), can have lasting effects on an HIV-infected patient's long-term prognosis. In one study,[8] an infant born to an HIV-infected mother began receiving ART within hours of birth. The infant tested positive for HIV and continued treatment for 18 months. Despite the HIV diagnosis and subsequent discontinuation of ART, the child remained virus-free one year later. A second baby with a similar history also showed an absence of HIV.[9] Together with several additional unconfirmed cases of babies "cured" of HIV infection, these findings offer hope to the ~250,000 babies born each year infected with HIV.[10]

3. ***Gut (Intestinal) Bacteria: The Microbiome Role in Autoimmune Disease***

NIH-funded research has shown that gut bacteria (the intestinal "microbiome"), which aid in food digestion, may impact the development of autoimmune diseases, including rheumatoid arthritis, type 1 diabetes, multiple sclerosis and inflammatory bowel disorders.[11] Current research is exploring changes in gut bacteria from diet, hormones, antibiotics, and infections, and the effect of gut bacteria based therapeutics [for example, the ingestion of healthy gut bacteria (probiotics) in yogurt]. One study involving fecal transplantation (which includes the transfer of intestinal bacteria from one person to another) has found that such transplantation in pill form is well tolerated and is 98-100% efficacious in curing infections with *Clostridium difficile*, a bacterium linked to ~14,000 diarrheal deaths in the U.S. per year.[12]

4. ***RSV Vaccine: Saving Infants' Lives***

Millions of infants are hospitalized and 160,000 children die each year each from pneumonia and other lung

diseases caused by respiratory syncytial virus (RSV).[13] Until recently, however, a vaccine for RSV has been elusive. In an important breakthrough, scientists at the NIH discovered antibodies – protective molecules produced by the immune system – that helped identify a key protein for use in vaccine development.[14] The NIH scientists were then able to engineer this protein and demonstrate its ability to produce a strong protective immune response against RSV in animals.[15] This molecule is expected to be ready soon for testing in humans. Importantly, the approach developed in this case can be applied to vaccine design for numerous other viruses, such as HIV, hepatitis C, dengue, and West Nile viruses, that have evaded the body's protective immune responses, and will provide insight into how viruses evade the immune system.

Conclusion

AAI thanks the members and staff of the subcommittee for their ongoing, strong bipartisan support for biomedical research, and recommends an appropriation of *at least $32 billion* for NIH for FY 2015 to fund important ongoing research, strengthen the biomedical research enterprise, and ensure that the brightest scientists, trainees, and students are able to pursue careers in biomedical research in the United States.

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[1] After a highly competitive peer review process, which includes comprehensive review by panels of extramural scientists, NIH awards more than 80% of its ~$30.1 billion budget to "more than 300,000 researchers at more than 2,500 universities, medical schools, and other research institutions in every state and around the world." About 10% of its budget supports the work of the approximately 6,000 scientists who work in NIH's own laboratories. (http://www.nih.gov/about/budget.htm)

[2] AAI is concerned that a federal policy limits government scientists' ability to attend privately sponsored scientific meetings and conferences. (See http://www.hhs.gov/travel/policies/2012_policy_manual.pdf) AAI believes that "the rules have had an unintended and deleterious effect ... [and] made government scientists feel cut off from the rest of the scientific community, wreaked havoc with their ability to fulfill professional commitments, and undermined the morale of some of the government's finest minds." *Testimony (Amended) of Lauren G. Gross, J.D., on behalf of The American Association of Immunologists (AAI), Submitted to the Senate Homeland Security and Governmental Affairs Committee for the Hearing Record of January 14, 2014: "Examining Conference and Travel Spending Across the Federal Government"* (http://aai.org/Public_Affairs/Docs/2014/AAI_Testimony_to_Senate_HSGAC_01142014.pdf)

[3] The Biomedical Research and Development Price Index (BRDPI) "is developed each year for NIH by the Bureau of Economic Analysis of the Department of Commerce. It reflects the increase in prices of the resources needed to conduct biomedical research, including personnel, services, supplies, and equipment.

It indicates how much the NIH budget must change to maintain purchasing power." Johnson, Judith A., "A History of NIH Funding: Fact Sheet," Congressional Research Service, R43341, p. 2 (2014)

[4] Ibid

[5] NIH should robustly fund and primarily rely on individual investigator-initiated research, in which researchers working in institutions across the nation submit applications to, and following independent peer review, receive grants from, NIH. Biomedical innovation and discovery are less likely to be achieved through "top-down" science, in which the government specifies the type of research it wishes to fund.

[6] Couzin-Frankel, Jennifer. "Cancer Immunotherapy." *Science* 342.6165 (2013): 1432-433

[7] Wolchok, J. D. et al. "Nivolumab plus Ipilimumab in Advanced Melanoma." *N Engl J Med* 369.2 (2013): 122-33

[8] Deborah, Persaud et al. "Absence of Detectable HIV-1 Viremia after Treatment Cessation in an Infant." *N Engl J Med* 369 (2013): 1828-835

[9] Conference on Retroviruses and Opportunistic Infections, March 3 - 6, 2014, Boston, MA (http://www.croi2014.org/) (See also http://www.nytimes.com/2014/03/06/health/second-success-raises-hope-for-a-way-to-rid-babies-of-hiv.html)

[10] A clinical trial following 60 babies born infected with HIV and being treated with antiretroviral medication will begin soon. (See http://www.nytimes.com/2014/03/06/health/second-success-raises-hope-for-a-way-to-rid-babies-of-hiv.html) A second study found that adult HIV-infected patients who were treated with ART within four months of infection display significantly improved response to treatment. [See Le, Tuan, et al. "Enhanced CD4+ T-Cell Recovery with Earlier HIV-1 Antiretroviral Therapy." *N Engl J Med* 368 (2013): 218-30]

[11] Sorini, C., and M. Falcone. "Shaping the (auto)immune Response in the Gut: The Role of Intestinal Immune Regulation in the Prevention of Type 1 Diabetes." *Am J Clin Exp Immunol* 2.2 (2013): 156-71

[12] Infectious Diseases Society of America. "Fecal Transplant pill knocks out recurrent C. diff infection," *Science Daily* (2013) (See http://www.cdc.gov/hai/organisms/cdiff/cdiff_infect.html)

[13] Couzin-Frankel, Jennifer. "Cancer Immunotherapy." *Science* 342.6165 (2013): 1432-433

[14] McLellan, J. S. et al. "Structure of RSV Fusion Glycoprotein Trimer Bound to a Pre-fusion Specific Neutralizing Antibody." *Science* 340.6136 (2013): 1113-117

[15] McLellan, J. S. et al. "Structure-Based Design of a Fusion Glycoprotein Vaccine for Respiratory Syncytial Virus." *Science* 342.6158 (2013): 592-98

COUNCIL ON SOCIAL WORK EDUCATION
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Testimony for Fiscal Year 2015
Programs funded within the Department of Health and Human Services and the Department of Education

Submitted to the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
March 27, 2014

Submitted by
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Council on Social Work Education
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On behalf of the Council on Social Work Education (CSWE), 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 to meet the health care needs of the nation through professional education, training, and financial support programs for social workers at the Department of Health and Human Services (HHS) and the Department of Education (ED). CSWE requests:

Agency	Account	Program	Funding Requested
HHS	HRSA	Title VII and Title VIII Health Professions Programs	$520 million
HHS	HRSA	Title VII Mental and Behavioral Health Education and Training Program	$10 million
HHS	SAMHSA	Minority Fellowship Program	$10 million, including at least $5.4 million for MFP core activities
ED	N/A	Pell Grant	$5,830 for the maximum Pell Grant
ED	N/A	GAANN	$31 million
ED	N/A	Loan Repayment Programs	Support without a cap on repayment

CSWE is a nonprofit national association representing more than 2,500 individual members and more than 700 master's and baccalaureate programs of professional social work education. Founded in 1952, this partnership of educational and professional institutions, social welfare agencies, and private citizens houses the sole accrediting body 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.

Recruitment and retention in social work continues to be a serious challenge that threatens the workforce's ability to meet societal needs. 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 2022, particularly for social workers specializing in the aging population and working in rural areas. The need for social workers specializing in mental health and substance use is expected to grow by 23 percent by 2022.[1]

CSWE understands the difficult funding decisions Congress is faced with. In these challenging times, it is my hope that the Committee will prioritize funding for health professions training in fiscal year (FY) 2015 to help to ensure that the nation continues to foster a sustainable, skilled, and culturally competent workforce that will be able to keep up with the increasing demand for social work services and meet the unique health care needs of diverse communities.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

TITLE VII AND TITLE VIII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide $$20 million in FY 2015 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through HRSA, which is equal to the FY 2012 enacted level. HRSA's Title VII and Title VIII health professions programs represent federal programs designed to train health care providers in an interdisciplinary way to meet the health care needs of all Americans, including the underserved and those with special needs, including expanding minority representation in the health care workforce. The Title VII and Title VIII programs, for which social workers and social work students are eligible, 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.

In the 2010 reauthorization of the Title VII and Title VIII programs, a new Title VII program was authorized in the *Patient Protection and Affordable Care Act* (P.L. 111-148), which recognized the severe shortages of mental and behavioral health providers within the health care workforce. The **Mental and Behavioral Health Education and Training Grants** program provides 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 program received first-time funding of $10 million in the final FY 2012 appropriations bill. The President's FY 2015 budget request would continue to support the program at HRSA and also through a partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA) to expand the mental health workforce by almost 3,500 professionals focused on transition-age youth (16-25). **CSWE urges the Committee to maintain funding at HRSA for this critically important program at the highest level possible in FY 2015 and include schools of social work as eligible entities.** CSWE supports the proposed expansion of the program but encourages the committee to be inclusive of non-youth populations needing mental and behavioral health services and not to reduce the scope of the original intent of the program through the expansion.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA) MINORITY FELLOWSHIP PROGRAM

CSWE urges the Committee to appropriate the highest level possible for the Minority Fellowship Program (MFP) in FY 2015. 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 use fields.[2] CSWE is one of six grantees of this critical program and administers funds to exceptional minority doctoral social work students. Other grantees include national organizations representing nursing, psychology, psychiatry, marriage and family therapy, and professional counselors.

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[1] U.S. Bureau of Labor Statistics. 2012. *Occupational Outlook Handbook: Social Workers, http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm*. Retrieved March 21, 2014.

[2] According to SAMHSA, minorities make up over one-fourth of the population, but less than 20 percent of behavioral health providers come from ethnic minority communities. Retrieved from SAMHSA Minority Fellowship Program, http://www.samhsa.gov/minorityfellowship/.

SAMHSA makes grants to these six organizations, who in turn recruit minority doctoral students into the program from the six distinct professions. CSWE administers the funds to qualified doctoral students and helps facilitate mentoring and networking throughout the duration of the fellowship as well as facilitates an alumni group to help continue to engage former fellows long after their formal fellowship has ended.

Since its inception in 1974, the MFP has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage therapists. Still, the program continues to struggle to keep up with the demands facing these 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 within Tribal communities, where mental illness and substance use 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. Also, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.[3] **The President's FY 2015 budget request includes $10 million for MFP activities. CSWE urges the committee to support this request, including at least $5.4 million for MFP core activities.**

DEPARTMENT OF EDUCATION: STUDENT AID PROGRAMS

CSWE supports full funding to keep the maximum Pell Grant at $5,830 in FY 2015. While Congress is understandably focused on identifying a solution that will place the Pell Grant program on solid ground in regards to its fiscal future, we urge you to remember that these grants help to ensure that all students, regardless of their economic situation, can achieve higher education. Moreover, as described above with regard to the SAMHSA Minority Fellowship Program, one goal of social work education is recruiting students from diverse backgrounds (which includes racial, economic, religious, and other forms of diversity)

[3] U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General.* Retrieved from http://www.surgeongeneral.gov/library/mentalhealth/cre/sma-01-3613.pdf.

with the hope that they will return to serve diverse communities once they have completed their education. In many cases, this includes encouraging social workers to return to their own communities and apply the skills they have acquired through their social work education to individuals, groups, or families in need. Without support such as Pell Grants, many low-income individuals would not be able to access higher education, and in turn, would not acquire skills needed to best serve in the communities that would most benefit from their service.

The Graduate Assistance in Areas of National Need (GAANN) program provides graduate traineeships in critical fields of study. Currently, social work is not defined as an area of national need for this program; however it was recognized by Congress as an area of national need in the Higher Education Opportunity Act of 2008. We encourage ED to recognize the importance of including social work in the GAANN program in future years. Inclusion of social work would help to significantly enhance graduate education in social work, which is critically needed in the country's efforts to foster a sustainable health professions workforce. **CSWE urges the Subcommittee to provide $31 million for the GAANN Program and include social work as an area of national need.**

CSWE supports efforts at ED to help students with high debt loads serve in low paying positions. The Income-Based Repayment (IBR) program and the Public Service Loan Forgiveness programs in particular help students graduating from social work programs who wish to serve in high-needs communities, often at a low salary level. **CSWE urges the Subcommittee to support loan repayment programs without a cap on repayment support at ED.**

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

COUNCIL OF ACADEMIC FAMILY MEDICINE

Association of Departments of Family Medicine
Association of Family Medicine Residency Directors
North American Primary Care Research Group
Society of Teachers of Family Medicine

Grant Hoekzema, MD
Chair, Council of Academic Family Medicine

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – March 28, 2014

FY 2015 FUNDING REQUESTS

We urge the Committee to appropriate at least $71 million for the health professions program, Primary Care Training and Enhancement, authorized under Title VII, Section 747 of the Public Health Service Act, under the jurisdiction of the Health Resources and Services Administration (HRSA.) In addition, we recommend the Committee fund the Agency for Healthcare Research and Quality (AHRQ) at no less than $375 million in base discretionary funding to support research vital to primary care.

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). The programs we support in our testimony are ones that deliver an investment in our nation's workforce and health infrastructure. They are a down payment on a US health care system with a foundation of primary care that will produce better health outcomes and reduce the ever rising costs of health care. We understand that hard decisions must be made in these difficult fiscal times, but even in this climate, we hope the Committee will recognize that the production of a robust primary care workforce for the future is a necessary investment that cannot wait and will ultimately produce long term savings.

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Primary Care Training and Enhancement

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of providing indispensible funding for the training of primary care physicians. With each successive reauthorization, Congress has modified the Title VII health professions programs to address relevant workforce needs. The most recent authorization directs the Health Resources and Services Administration (HRSA) to prioritize training in the new competencies relevant to providing care in the patient-centered medical home model. It also calls for the 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. Departments of family medicine and family medicine residency programs often rely on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery.

There has not been a competitive cycle for these grants since FY2010. There are currently over 200 grants, completing their cycle in FY2014 who will be eligible to apply in FY2015, as well as numerous other potential applicants who did not receive funding in FY2010. The current funding level (approximately $36.9 million) is not enough to allow for the pent up demand. More importantly, the vital work of these grants to help reform primary care education and the health delivery system needs to be prioritized.

As implementation of the Affordable Care Act proceeds with increasing numbers of insured persons, the nation will need new initiatives relating to increased training in inter-professional care, the patient-centered medical home, and other new competencies required in our developing health system. Such initiatives will be impossible to implement without a competitive grant cycle with enough funding to allow for a robust result of new grants. Now is the time to ensure that critical funding for the Primary Care Training and

Enhancement program takes place. Title VII has a profound impact on states across the country and is vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. We cannot allow the primary care pipeline to dry up.
Below are some examples of how these grants have made lasting contributions:

"With funding from a Title VII Medical Student Education grant, we were able to expand our existing medical student family medicine clerkship clinic to include students from pharmacy, nursing, occupational and physical therapy, and law, who see patients together under the supervision of faculty from all disciplines. This has allowed us to create one of the few truly interprofessional clinical experiences." Joshua Freeman, MD, Chair, Department of Family Medicine, University of Kansas School of Medicine

"Our AAU HRSA Title VII Grant has allowed us to transform the education of medical students and residents at Brown University around the patient centered medical home, including new curricula and rotations, as well as the facilitation work to transform 10 family medicine teaching practices. In addition, we have run 3 national "think tanks" to discuss practical and theoretical issues related to models for practice transformation, PCMH evaluation, and the Adolescent PCMH. This grant has had huge impact and the work could not have been done without it. Jeffrey Borkan, MD, PhD, Chair, Department of Family Medicine, Brown University

"Previous grants included starting a resident continuity clinic at an FQHC, and preparation for rural training (rural continuity clinic, curriculum, rural mentoring program, rural medicine interest group). More distant grants help set up rural training sites for medical students and residents in 1975 and 1980, both of which are still providing that important function. Steven C. Zweig, MD, MSPH, Chair, Department of Family Medicine, University of Missouri"

Agency for Health Care Research and Quality (AHRQ)

Two years ago, we were disappointed to see the subcommittee eliminate funding for AHRQ in its draft bill. We understand that in our current budgetary climate it is important to leverage research funding in the most effective ways possible. However, the majority of research funding supports research of one specific disease, organ system, cellular, or chemical process – not for primary care. This is in spite of the fact that the overall health of a population is directly linked to the strength of its primary health care system. Primary care research includes: translating science into the practice of medicine and caring for patients, understanding how to better organize health care to meet patient and population needs, evaluating innovations to provide the best health care to patients, and engaging patients, communities, and practices to improve health. AHRQ is uniquely positioned to support this sort of best practice research and to help advance its dissemination to improve primary care nationwide.

There are six areas that we believe AHRQ excels at – and that are not available elsewhere in the biomedical research infrastructure: primary care research through Practice-based Research Networks (PBRNs), practice transformation, patient quality and safety in non-hospital settings, multi-morbidity research, mental and behavioral health provision in communities and primary care practices, and training future primary care investigators. Critical to the successful engagement and development of primary care research is the constraint of not having an adequate cadre of well-trained researchers. We believe there is a need to deliberately promote this training as a way to aid in the development of all the areas we have emphasized. AHRQ has researcher training mechanisms in place, which we believe are important, and need to be expanded.

Some examples from the field regarding the utility of AHRQ-funded grants:

"Three AHRQ grants supported the development of patient centered personal health records in 2007, 2009, and 2010, and studied whether these tools increased prevention. In our studies we found increases in important tests like colon and breast cancer screening as well as immunizations, blood pressure and cholesterol control. In addition, we were able to leave the functionality in place – permanently – for 191 doctors and now 60,000 patients. One result is that the practices are now using the AHRQ created portal as their sole patient portal and abandoned the commercial portal that did not work as well." Alex Krist, M.D., M.P.H., Virginia Commonwealth University

"The AHRQ-sponsored series of grants on Multiple Chronic Condition research were transformative for that field. They also sponsored regular meetings among grantees and established the Multiple Chronic Conditions Research Network, which has fostered many collaborations between researchers with shared expertise." Elizabeth A. Bayliss, MD, MSPH, Kaiser Permanente Colorado

Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians treat is lacking. AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. This research is essential to create a robust primary care system for our nation -- one that delivers higher quality of care and better health while reducing the rising cost of care. Despite this need, little is known about how patients can best decide how and when to seek care, how to introduce and disseminate new discoveries into real life practice, and how to maximize appropriate care. This type of research requires sufficient funding for AHRQ, so it can help researchers address the problems confronting our health system today.

We recommend the Committee fund AHRQ at a base, discretionary level of at least $375 million for Fiscal Year 2015.

Statement of the American Academy of Family Physicians

Statement to the House Committee on Appropriations
Concerning the Bill to Fund the Departments of Labor, Health and Human Services, & Education, and Related Agencies Appropriations for FY 2015

March 28, 2013

The American Academy of Family Physicians (AAFP), representing 110,600 family physicians and medical students nationwide, urges the House Appropriations Subcommittee on Labor, Health and Human Services, and Education to invest in our nation's primary care physician workforce in the fiscal year 2015 appropriations bill to promote the efficient, effective delivery of health care by providing these appropriations for the Health Resources and Services Administration and the Agency for Healthcare Research and Quality:

- $71 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the *Public Health Service Act* (PHSA);
- $10 million for Teaching Health Centers development grants (PHSA Title VII, §749A);
- $4 million for Rural Physician Training Grants (PHSA Title VII, §749B);
- $100 million for the National Health Service Corps (PHSA § 338A, B, & I);
- $375 million for the Agency for Healthcare Research and Quality (PHSA § 487(d)(3), *SSA* §1142); and
- $3 million for the National Health Care Workforce Commission (ACA § 5101).

Founded in 1947, the AAFP is dedicated to preserving and promoting the science and art of family medicine and ensuring high-quality, cost-effective health care for patients of all ages. The AAFP appreciates the opportunity to comment on the FY 2015 appropriations levels needed to achieve those important goals.

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HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Our nation faces a shortage of primary care physicians. The total number of office visits to primary care physicians is projected to increase from 462 million in 2008 to 565 million in 2025 requiring nearly 52,000 additional primary care physicians by 2025.[1] The Health Resources and Services Administration (HRSA) is the federal agency charged with administering the health professions training programs authorized under Title VII of the *Public Health Services Act* and first enacted in 1963. We urge the Committee to restore funding for discretionary HRSA programs to the FY 2010 level of $7.48 billion in the FY 2015 bill.

Title VII Health Professions Training Programs – In the last 50 years, Congress has revised the Title VII authority in order to meet our nation's changing health care workforce needs. We now face burgeoning demand for family physicians and must work to increase their number in the United States. As the only medical specialty society devoted entirely to primary care, the AAFP is gravely concerned that a failure to provide adequate funding for the Title VII, Section 747 Primary Care Training and Enhancement (PCTE) program, will destabilize education and training support for family physicians. Between 1998 and 2008, in spite of persistent primary care physician shortages, family medicine lost 46 training programs and 390 residency positions, and general internal medicine lost nearly 900 positions.[2] A study published in the *Annals of Family Medicine* on the impact of Title VII training programs found that physicians who work with the underserved in Community Health Centers and National Health Service Corps sites are more likely to have trained in Title VII-funded programs.[3] Title VII primary care training grants are vital to departments of family medicine, general internal medicine, and general pediatrics; they strengthen curricula; and they offer incentives for training in underserved areas. In the coming years, medical services utilization is likely to rise

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[1] Petterson, S, et al. Projecting US Primary Care Physician Workforce Needs: 2010-2015. Ann Fam Med 2012; vol.10 no. 6:503-509.
[2] Phillips RL and Turner, BJ. The Next Phase of Title VII Funding for Training Primary Care Physicians for America's Health Care Needs. Ann Fam Med 2012; vol.10 no. 2:163-168.
[3] Rittenhouse DR, et al. Impact of Title VII training programs on community health center staffing and national health service corps participation. Ann Fam Med 2008; vol. 6 no. 5:397-405.

given the increasing and aging population as well as the insured status of more people. These demographic trends will exacerbate family physician shortages. Although PCTE grants are important to family medicine, there has not been a competitive cycle for these grants since FY 2010. The AAFP urges the Committee to increase the level of federal funding for primary care training to at least $71 million in FY 2015 to allow for a robust new grant cycle to support family medicine education and training in the new competencies required to meet the needs of patients of all ages.

Teaching Health Centers – The AAFP has long called for reforms to graduate medical education programs to encourage the training of primary care residents in non-hospital settings where most primary care is delivered. An excellent first step is the innovative Teaching Health Centers (THC) program authorized under Title VII, § 749A to increase primary care physician training capacity that HRSA administers. Federal financing of graduate medical education has led to training mainly in hospital inpatient settings even though most patient care is delivered outside of hospitals in ambulatory settings. The THC program provides resources to any qualified community based ambulatory care setting that operates a primary care residency. We believe that this program requires an investment of $10 million in FY 2015 for planning grants.

Rural Physician Workforce Needs – HRSA's Office of Rural Health focuses on rural health policy issues and administers rural grant programs. As the medical specialty most likely to enter rural practice, family physicians recognize the importance of dedicating appropriate resources to rural health needs. A recent study found that medical school rural programs have had a significant impact on rural family physician supply and called for wider adoption of that model to substantially increase access to care in rural areas compared to a greater reliance on international medical graduates or unfocused expansion of traditional medical

schools.[4] HRSA's Rural Physician Training Grant program will help medical schools recruit students most likely to practice medicine in rural communities. This program will help provide rural-focused experience and increase the number of medical school graduates who practice in underserved rural communities. The AAFP recommends that the Committee provide $4 million for Rural Physician Training Grants in FY 2015 as called for in the President's budget request.

Primary Care in Underserved Areas – The National Health Service Corps (NHSC) recruits and places medical professionals in Health Professional Shortage Areas to meet the need for health care in rural and medically underserved areas. The NHSC offers scholarships or loan repayment as incentives for physicians to enter primary care and provide health care to Americans in Health Professional Shortage Areas. By addressing medical school debt burdens, the NHSC also helps to ensure wider access to medical education opportunities. The President's budget request includes $810 million for the NHSC, of which $710 million is mandatory funding. If the NHSC is funded at the President's requested level in FY 2015, underserved patients will benefit from an NHSC field strength of more than 15,400 primary care clinicians compared to the FY 2013 field strength of 8,899. The AAFP supports the President's budget request for this important program and recommends that the Committee provide an appropriation of $100 million for the NHSC in FY 2015 to supplement the authorized and requested mandatory funds.

AGENCY FOR HEATLHCARE RESEARCH AND QUALITY (AHRQ)

AHRQ is the only federal agency responsible for generating evidence to make health care safer; better; and more accessible, equitable and affordable. AHRQ provides the critical evidence reviews that the AAFP and other physician specialty societies use to produce clinical practice guidelines. These evidence-informed

[4] Rabinowitz,HK, et al. Medical School Rural Programs: A Comparison With International Medical Graduates in Addressing State-Level Rural Family Physician and Primary Care Supply. Academic Medicine, Vol. 87, No. 4/April 2012.

guidelines are important to family physicians as well as to patients and their families. AHRQ takes the results from the NIH whose research restricts subjects to limit the variables in clinical studies and brings the practical information to the practicing physicians who treat patients without those clinical restrictions. ARHQ supports critical primary care investigations through Practice-based Research Networks that examine practice transformation, patient quality and safety in non-hospital settings, multi-morbidity research, as well as mental and behavioral health care in communities and primary care practices. The AAFP asks that the Committee provide $375 million in base discretionary funding for AHRQ in FY 2015.

NATIONAL HEALTH CARE WORKFORCE COMMISSION

Appointed on September 30, 2010, the 15-member National Health Care Workforce Commission was intended to serve as a resource with a broad array of expertise. The Commission was directed to analyze current workforce distribution and needs; evaluate health care education and training; identify barriers to improved coordination at the federal, state, and local levels and recommend ways to address them; and encourage innovations. There is broad consensus about the waning availability of primary care physicians in the United States, but estimates of the severity of the regional and local shortages vary. The AAFP supports the work of the Commission to analyze primary care shortages and propose innovations to help produce the physicians that our nation needs and will need in the future. We request that the Committee provide $4 million in FY 2015 so that this important Commission can finally begin this important work.

National Association of RSVP Directors

STATEMENT OF MS. BETTY RUTH, PRESIDENT OF THE NATIONAL ASSOCIATION OF RSVP DIRECTORS (NARSVPD) TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

WASHINGTON, DC, MARCH 25, 2014:

Members of the Subcommittee:

NARSVPD members seek funding for the RSVP program administered by the Corporation for National and Community Service at $50.2 million.

We object to the Admi9nistration's proposal to effectively end the RSVP program and turn its back on a distinguished history of senior service stretching back more than 40 years.

These proposals represent a sneak attack on seniors. The Administration did not present this proposal for public discussion. It did not reach out to the three senior associations to work collaboratively to address its concerns. It did not seek input from stakeholders who work with RSVP. It did not ask Congress to consider these proposals in the context of a reauthorization; a deliberative process. Instead it sprung this revolutionary change on an unsuspecting field.

The greater tragedy is that the Budget Justification does not justify this proposal. RSVP works. It deploys 300,000 volunteers across the nation at an average annual cost of less than $175 per volunteer. In FY 12, those volunteers

- Served 563,200 veterans in activities such as transportation and employment service referrals;
- Mentored more than 82,590 children;
- Provided independent living services to 742,800 adults, primarily □frail seniors.
- Provided respite services to nearly 24,000 family or informal □caregivers; and
- Engaged 24,450 veterans who served as RSVP volunteers.

It also breaks faith with the provisions of the Kennedy Serve America Act (SAA).

On March 17, 2009, the Administration released a Statement of Administration Policy about the so-called GIVE Act, the precursor to the SAA. That Statement said "The Administration has called upon Americans from all walks of life to take part in civic renewal, and is therefore pleased that H.R. 1388 also would expand and improve service opportunities for seniors. **In particular, the Administration applauds the responsible and balanced introduction of competition into the Retired Senior Volunteer Program, which would better position the program for expansion. [Emphasis added].**"

RSVP programs have competed for funds for the last two years. To put it mildly, there has been no expansion. Rather, the Administration has continued to take aim at RSVP and the other senior volunteer programs.

The Budget ignores the Serve America Act, which authorized the Corporation to:

"(iv) ensure that—

□"(I) the grants or contracts awarded under this section through the competitive process for a grant or contract cycle support an aggregate number of volunteer service years for a given geographic service area that is not less than the aggregate number of volunteer service years supported under this section for such service area for the previous grant or contract cycle;

"(II) the grants or contracts awarded under this section through the competitive process for a grant or contract cycle maintain a similar program distribution, as compared to the program distribution for the previous grant or contract cycle; and

"(III) every effort is made to minimize the disruption to volunteers; and□ (v) include the use of performance measures, outcomes, and other criteria established under subsection (g)."

The Administration's proposal accomplishes exactly the opposite.

The Corporation CBJ admits that (page 62) competition is working. And it is. Weaker programs are being weeded out and replaced by stronger ones. The service is more focused and evidence-based.

The Administration proposal provokes more questions than it answers. Assuming this proposal was to be enacted into law:

The guiding principles of National Service are to create opportunities for all Americans to serve and to do as much as possible to recognize where people are in the life cycle. This proposal does neither. It cuts the number of seniors serving and forces others into a model that won't work for many of them.

A more thoughtful approach would have been to ask how we could expand senior volunteer service to take advantage of the talents and experiences of the 10,000 Baby Boomers who are retiring today and will do so every day for the next 20 years. What would need to be done to build on RSVP's infrastructure and network of public agencies and private nonprofits? This proposal is short sighted and has no vision.

In short, we urge that the Administration withdraw this proposal.

Thank you for the opportunity to present our views on the President's FY 2015 Budget for the Corporation.

For additional information, please contact Ms. Betty Ruth, President of NARSVPD at bruth@al-rsvp.com or Gene Sofer, NARSVPD Washington Representative, at eugenesofer@gmail.com or 202-363-6101.

Written Testimony Submitted to the House Committee on Appropriations
Subcommittee on Labor, Health and Human Services Education, and Related Agencies
Rachel Wilson, MPH, Senior Director of Policy and Advocacy, PATH
March 28, 2014

Thank you for the opportunity to submit written testimony in support of fiscal year 2015 funding for global health and immunization initiatives at the US Department of Health and Human Services (HHS). PATH is an international nonprofit that drives transformative innovation to save lives and improve health in developing countries, especially among women and children. PATH accelerates innovation across five platforms—vaccines, drugs, diagnostics, devices, and system and service innovations. We actively collaborate with partners—including the US government—to develop new and adapt existing innovations across the health spectrum. The focus of this testimony is HHS's role in immunization in the developing world. HHS is a key partner to PATH in our efforts to develop and accelerate the introduction of vaccines into poor countries and to ensure that sustainable systems and support exist to get vaccines to those most at risk. As an organization that partners with the public and private sectors here at home and in more than 70 other countries, we see firsthand the impact of US government investments in global health.

We respectfully request that this Subcommittee allocate full funding for the US Centers for Disease Control and Prevention (CDC), with $464 million at the CDC Center for Global Health (including the Global Immunization Division), and $432 million for the CDC Center for Emerging and Zoonotic Infectious Diseases; $32 billion for the National Institutes of Health (NIH), especially programs that support global health research and development (R&D); and, full funding for cross-cutting global immunization coordination and leadership functions performed by HHS headquarters.

We are grateful for the continued leadership of Chairman Kingston and Ranking Member DeLauro, and acknowledge the challenge the Subcommittee faces in prioritizing programs to serve the diverse needs of the American people. Infectious diseases do not respect borders. For this reason, the CDC has been the global leader in detecting epidemic threats earlier, responding more effectively, and preventing avoidable health catastrophes. Similarly, the NIH has been the world's leading investor in the development of new health technologies that can be used to protect lives at home and abroad from debilitating and deadly diseases.

The vital role of HHS in global health and immunization

The health of US citizens is inherently connected to the health of people living around the globe. Global pandemics and increasing overseas travel in recent decades have intensified Americans' vulnerability to infectious diseases found in other countries. Recognizing this, HHS has been active in global health programs for decades. In recent years, HHS developed the Global Health Strategy (2011) and the Global Health Security Agenda (2014) to better protect Americans' health and security while improving health around the world. A key strategy for achieving these global health goals is immunization.

Vaccines are one of the most impactful public health interventions available today. The number of children under the age of five dying each year has fallen below 6.6 million—roughly half the number of deaths in 1990—largely due to the introduction of new vaccines as well as strengthened delivery systems. HHS programs can be credited with some of this significant impact. Polio cases have dropped by more than 99 percent since 1988, measles deaths declined by 74 percent from 2000 through 2010, and more than 2.5 million deaths are averted each year through routine immunization. Extending the reach of lifesaving vaccines to where they are

needed most can save even more lives, contributing to healthier, more productive communities. Vaccines are also one of the most cost-effective public health tools.

Global immunization is one of five core objectives of the US National Vaccine Plan (2010-2015), emphasizing its role in providing an "umbrella of protection" for the United States. Following up on this recommendation, the National Vaccine Advisory Committee developed a series of recommendations on how HHS can best continue to contribute to these efforts, consistent with Global Health Strategy and the National Vaccine Plan. Full funding is needed to execute these strategies and support the dual objectives of protecting the health of Americans while improving children's lives overseas.

Protecting US leadership in global health R&D

While access to existing vaccines is extended, it is also critical to support R&D into future vaccines and immunization technologies that can prevent existing and emerging global health threats. Investments made by the US government, including through the NIH and CDC over the past three decades, have enabled many partners, including PATH, to advance innovations that have strengthened immunization programs throughout the world. Among them are new and improved vaccines for meningitis A and Japanese encephalitis, and new safe-injection technologies that have helped to prevent millions of new vaccine-related, blood-borne infections. Additionally, PATH and our partners have improved vaccine technologies and delivery systems to allow immunization programs to extend their reach.

The promise of new vaccines and immunization technologies can only be realized when products are developed, tested, and scaled up for use globally. Strengthened collaboration and coordination between HHS operating divisions and other US agencies funding vaccine

development and delivery—namely, the US Agency for International Development and the Department of Defense—will be critically important to better align vaccine R&D investments and vaccination program priorities across the US government to maximize the impact of US taxpayer dollars.

Supporting vaccine introduction

CDC and other partner agencies play a key role in ensuring that appropriate vaccines are introduced and widely available where they are needed most. When new and improved vaccines become available, countries must weigh several factors when deciding whether or not, and how, to introduce the vaccine. CDC provides valuable epidemiological, laboratory, and policy expertise to help build the capacity of countries to make informed decisions and plan for incorporating new vaccines into their immunization program. For example, in Nigeria, CDC is using Geographic Information Systems (GIS) to help the health ministry locate nomadic populations and plan immunization activities; and, in three Central African countries, CDC is empowering health workers to prevent disease and control outbreaks through enhanced disease reporting, which also allows for better allocation of limited resources.

Strengthening global immunization systems

Immunization systems are composed of the people, processes, tools, and equipment that effectively deliver vaccines into the communities where they are needed. CDC and partner agencies, including domestic health ministries and the World Health Organization, ensure that health systems are robust enough to operate effective immunization programs. One component of the immunization system is the cold chain, which safely transports vaccines from point of manufacture to point of delivery. Most current vaccines are required to be kept within a specific

temperature range, in order to maintain their potency. However, as new vaccines are introduced, the existing infrastructure will need upgrading to address both the aging of equipment and the need for additional capacity.

To help countries meet these needs, CDC assists in the development of global guidelines, trains country nationals to evaluate their cold chains, and provides needed improvements to enable effective vaccine transport. CDC also helps train the health workforce and identifies where it may be appropriate to use immunization sessions to also deliver other public health prevention interventions, such as vitamin A supplements. Additionally, CDC contributes to strengthening overall systems through its disease-focused work on polio and measles. Through these programs, CDC helps protect investments made in the purchase of vaccines and improves the impact of programs.

Vaccines: the foundation for global health

By supporting the development of new vaccines, research into new and improved vaccine delivery technologies, and improving access to existing vaccines across the globe, the US can help protect the health of Americans while ensuring that people everywhere have the opportunity to lead healthy, productive lives. By fully funding the global health and immunization-related accounts, the United States can continue its role as a global leader in health care while improving security at home and abroad.

Prevent Blindness
Written Testimony to the House Appropriations
Labor, Health and Human Services, Education, and Related Agencies Subcommittee
Submitted by: Hugh Parry, President & CEO, Prevent Blindness
March 28, 2014

Funding Request Overview

Prevent Blindness respectfully requests that the Subcommittee provide the following allocations in fiscal year (FY) 2015 to help promote eye health and prevent eye disease and vision loss:

- Provide at least $1,000,000 to strengthen the Vision Health Initiative (visual screening education) at the Centers for Disease Control and Prevention (CDC).
- Provide at least $3,319,000 to continue the Glaucoma Project at the CDC.
- Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health.
- Provide at least $639 million in to sustain programs under the Maternal and Child Health (MCH) Block Grant.
- Provide at least $730 million to the National Eye Institute (NEI).

Introduction and Overview

Vision-related conditions affect people across the lifespan. 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, and is a leading cause of impaired health in childhood. Recent research showed that the economic burden of vision loss and eye disorders is $139 billion each year, $47.4 billion of which is federal spending.

Alarmingly, while half of all blindness can be prevented through education, early detection, and treatment, the NEI reports that "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."

To curtail the increasing incidence of vision loss in America, and its related economic burden, Prevent Blindness advocates sustained and meaningful federal funding for programs that 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 recognize the challenges facing the Subcommittee and urge you to consider the ramifications of decreased investment in vision and eye health. Vision loss is often preventable, but without continued efforts to better understand eye conditions, and their treatment, through research, to develop the public health systems and infrastructure to disseminate and implement good science and prevention strategies, and to protect children's vision, millions of Americans face the loss of independence, loss of health, and loss of their livelihoods, all because of the loss of their vision.

Vision and Eye Health at the CDC: Helping to Save Sight and Save Money

The CDC serves a critical role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness have collaborated with other partners to create a more effective public health approach to vision loss prevention and eye health promotion. The CDC works to promote eye health and prevent vision loss; improve the health and lives of people living with vision loss by preventing complications, disabilities, and burden; reduce vision and eye health related disparities; and integrate vision health with other public health strategies. However, severely constrained financial resources have limited the CDC's ability to take the work of the Vision Health Initiative (VHI) to the next level.

Prevent Blindness requests at least $1,000,000 in FY 2015 to strengthen vision and eye health efforts of the CDC. This funding level would allow the VHI to increase vision impairment and eye disease surveillance efforts, apply previous CDC vision and eye health research findings to develop effective prevention and early detection interventions, and begin to incorporate vision and eye health promotion activities into state and national public health chronic disease initiatives, with an initial focus on early detection of diabetic retinopathy

Improving Access to Eye Care for those at High Risk for Glaucoma

An estimated 2.2 million people are affected by glaucoma. A disease of the aging eye, risk for glaucoma increases with age, especially among black, Hispanic/Latinos, and Asians. Once vision is lost to glaucoma, it cannot be restored, but with early diagnosis and appropriate treatment, it is possible to slow disease progression and save the remaining sight. Detection and management of glaucoma are challenged by difficulties in reaching high-risk populations and by the lack of simple, cost-effective screening plans.

Prevent Blindness requests at least $3,319,000 in FY 2015 to continue the work of the Glaucoma Project to improve glaucoma screening, referral, and treatment. The program is intended to reach those populations experiencing the greatest disparity in access to glaucoma care through an integrated collaboration among private and public organizations.

Investing in the Vision of Our Nation's Most Valuable Resource – Children

The visual system in children younger than 8 years old is in a critical developmental stage. Unidentified and untreated vision problems can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Currently, only one in three children receives eye care services before the age of six. Requirements for preventive eye care/vision screenings prior to or during the school years vary broadly from state to state, most

with no standardization regarding age-appropriate methods, referral procedures, or follow-up requirement protocols. Inclusion of vision screenings with a comprehensive approach to follow up treatment and data collection will help to change disparities in vision and eye health for our nation's children.

In 2009, the MCHB established the National Center for Children's Vision and Eye Health (NCCVEH), 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.

NCCVEH is guided by an Advisory Committee comprised of the nation's leaders in children's vision and public health to implement national guidelines for quality improvement strategies, vision screening and developing a continuum of children's vision and eye health. With this support the Center, will continue to: (1) provide national leadership in dissemination of best practices, infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye health care for children; (2) advance state-based performance improvement systems, screening guidelines, and mechanisms for uniform data collection and reporting; and (3) provide technical assistance to states in the implementation of strategies for vision screening, establishing quality improvement measures, and improving mechanisms for surveillance.

Prevent Blindness also requests at least $639 million in FY 2015 to sustain programs under the MCH Block Grant. The MCH Block Grant enables states to expand critical health care services to millions of pregnant women, infants and children, including those with special health

care needs. In addition to direct services, the MCH Block Grant supports programs, preventive and systems building services needed to promote optimal health – including NCCVEH.

Advance and Expand Vision Research Opportunities

Prevent Blindness calls upon the Subcommittee to provide $730 million for the NEI to enable the agency to pursue its primary "audacious goal" of restoring vision by bolstering 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. By providing additional 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, 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 2015 funding for the CDC's vision and eye health efforts, the MCHB's the Center , and the NEI. Please know that Prevent Blindness 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.

***Prevent Blindness** – the nation's leading non-profit, voluntary organization committed to preventing blindness and preserving sight – 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. For more information about Prevent Blindness and our federal government relations and public policy efforts, please visit www.preventblindness.org*

Testimony of the American Academy of Pediatrics
Concerning Fiscal Year 2015 Appropriations
Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
March 27, 2014
Submitted by: James, Perrin, MD, FAAP, President, American Academy of Pediatrics

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The American Academy of Pediatrics (AAP), a non-profit professional organization of 62,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record in support of strong federal investments in children's health in Fiscal Year 2015 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term federal spending decisions. AAP supports robust investment in programs that help ensure the health, safety and well-being of children, including $5 million for the Pediatric Subspecialty Loan Repayment Program at the Health Resource Services Administration (HRSA), $21 million for the Emergency Medical Services for Children (HRSA), $139 million for the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC), and $160 million for Polio Eradication and $49 million for the Measles program within CDC.

Every adult was once a child. Many adult diseases have their origins in childhood. Early and continued investments in our children's health are needed to prevent obesity, heart disease, substance use, and other chronic conditions that threaten America's health and fiscal solvency. As clinicians we not only diagnose and treat our patients, we also promote preventive interventions to improve overall health. Likewise, as policymakers, you have an integral role in ensuring the health of future generations through adequate and sustained funding of vital federal programs.

Pediatric Subspecialty Loan Repayment Program

The United States' supply of pediatric subspecialists is inadequate to meet children's health needs. Many children must wait more than 3 months for an appointment with a pediatric subspecialist. Approximately 1 in 3 children must travel 40 miles or more to receive care from a pediatrician certified in adolescent medicine, developmental behavioral pediatrics, neurodevelopment disabilities, pulmonology, emergency medicine, nephrology, rheumatology, and sports medicine. This problem is compounded by the fact that fewer medical residents are choosing careers in pediatric subspecialties, and the existing subspecialist workforce continues to age. There is also a significant disparity in the geographic distribution of pediatric subspecialists across the country, resulting in many underserved rural and urban areas.

The Pediatric Subspecialty Loan Repayment Program (PSLRP) seeks to expand children's access to healthcare by creating a more robust pediatric work force. In the program, eligible participants must agree to practice full-time for not less than two years in a pediatric medical specialty, surgical specialty, or a child or adolescent mental and behavioral subspecialty in a health professional shortage area or a medically underserved area. In return, the program will pay up to $35,000 in loan repayment for each year of service, for a maximum of three years.

FY2015 Request: $5 million; FY 2014 Level: Not Funded.

Emergency Medical Services for Children

Established by Congress in 1984 and last reauthorized in 2010, the Emergency Medical Services for Children (EMSC) Program is the only federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. Currently celebrating its 30th year, the EMSC program has made landmark improvements to the emergency care delivered to children all across the nation. EMSC aims to ensure that state of

the art emergency medical care for the ill and injured child or adolescent is well integrated into an EMS system. Every state has received EMSC funds, which they have used to ensure that hospitals and ambulances are properly equipped to treat pediatric emergencies, to provide pediatric training to paramedics and first responders, and to improve the systems that allow for efficient, effective pediatric emergency medical care.

Continued support for EMSC has allowed the program to maintain its existing activities, improve pediatric capacity and transport of pediatric patients, and address emerging issues such as pediatric emergency care readiness and pediatric emergency medical services in rural and remote areas.

FY 2015 Request: $21 million; FY 2014 Level: $20.1 million.

National Center for Birth Defects and Developmental Disabilities

The National Center for Birth Defects and Developmental Disabilities is a center within CDC that seeks to promote the health of babies, children, and adults and enhance the potential for full, productive living. According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States; the center has done tremendous work in the way of identifying the causes of birth defects and developmental disabilities, helping children to develop and reach their full potential. The center also conducts important research on fetal alcohol syndrome, infant health, autism, congenital heart defects, and other conditions like Tourette Syndrome, Fragile X, Spina Bifida and Hemophilia. NCBDDD has proven to be an asset to children and their families and supports extramural research in every State. FY 2015 Request: $139 million; FY 2014 Level: $122.4 million.

Global Health at CDC

The AAP calls on Congress to support and resource Health and Human Services to implement the recommendations of the National Vaccine Advisory Committee of the Global Immunizations Working Group on enhancing the work of the HHS National Vaccine Program in Global Immunizations. This includes support for HHS' role in building international cooperation for the common goal of reducing the burden of vaccine-preventable diseases. HHS has unique and timely opportunities to eradicate polio, to reduce measles mortality, and to ensure that the routine immunization systems at the front lines of these efforts are maintained. The funding that Congress provides to CDC's Global Immunization account is also necessary to act on the Advisory Committee's recommendations that HHS enhance its ongoing efforts to strengthen global immunization systems, enhance global capacity for vaccine safety monitoring and post-marketing surveillance, build global immunization research and development capacity, and strengthen countries' capacity for vaccine decision making.

Since 1988 a coordinated global immunization campaign has reduced the number of polio cases globally by more than 99 percent, saving more than 10 million children from paralysis and bringing the disease close to eradication. Expanded immunization has reduced the global mortality attributed to measles by 74 percent between 2000 and 2010.

Polio FY 2015 Request: $160 million; FY 2014 Level: $146 million
Measles FY 2015 Request: $49 million; FY 2014 Level: $42.2 million

America's children deserve better

Twenty two percent of children in the United States now live in poverty – up from 17 percent in 2007. Many children suffer from food insecurity, unstable housing, family dysfunction, abuse and neglect. Such adverse childhood experiences are linked with "toxic stress," a biologic phenomenon associated with profound and irreversible changes in brain anatomy and chemistry that have been implicated in the development of health-threatening behaviors and medical

complications later in life including drug use, obesity, and altered immune function. Adults affected by such adverse childhood experiences are more likely to have experienced school failure, gang membership, unemployment, violent crime, and incarceration.

Healthier children, healthier future

On behalf of the 75 million American children and their families that we serve and treat, the nation's pediatricians expect Congress to respond to mounting evidence that child health has life-long impacts and put children first during appropriations negotiations. Investing in children is not only the right thing to do for the long-term physical, mental, and emotional health of the population, but is imperative for the nation's long-term fiscal health as well. In addition to the programs we have specifically mentioned in this testimony, federal support for children's health programs, such as early brain and child development, parenting and health education, and preventive health services, will yield high returns for the American economy. Cuts to these areas in the short-term will blunt the possible long-term savings these programs could achieve.

We fully recognize the nation's fiscal challenges and respect that difficult budgetary decisions must be made; however, we do not support funding decisions made at the expense of the health and welfare of children and families. Rather, a focus on the long-term needs of children and adolescents will ensure that the United States can compete in the modern, highly-educated global marketplace. Strong and sustained financial investments in children's health care, research, and prevention programs will help keep our children healthy and pay dividends for years to come.

The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our nation's children in Fiscal Year 2015 and beyond. If we may be of further assistance please contact the AAP Department of Federal Affairs at 202-347-8600 or aperleoni@aap.org. Thank you for your consideration.

Testimony of Gina Gavlak, R.N., BSN
Chair, National Advocacy Committee, American Diabetes Association
Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, United States House of Representatives
Contact: Tekisha Dwan Everette, Managing Director, American Diabetes Association, 703-253-4375, teverette@diabetes.org

Thank you for the opportunity to submit testimony on behalf of the American Diabetes Association (Association). For Fiscal Year (FY) 2015, the Association urges the Subcommittee to make a substantial investment in research and prevention efforts to find a cure, and improve the lives of those living with, and at risk for, diabetes. We ask the Subcommittee to provide $2.066 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), $137.3 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and $20 million in funding for the National Diabetes Prevention Program at CDC.

I have been living with type 1 diabetes since I was 10 years old. I remember listening as the doctor told my mom that I would never be able to have children and that diabetes would shorten my life. Well, I've proved him wrong – thanks to the many medical discoveries and advancements at the NIH and translational research from CDC, I have two beautiful children and have lived 34 years with diabetes, without complications. I am proud to share my testimony with you on behalf of the nearly 105 million American adults and children living with diabetes or prediabetes.

Diabetes is a disabling, deadly, and growing epidemic. According to the CDC, one in three adults in our country – one in two among minority populations – will have diabetes in 2050 if present trends continue. As a person living with diabetes who is also an emergency room and diabetes nurse, I see the human and economic toll diabetes extracts from my patients and their families. The lives of people living with, and at risk for, diabetes are better because of NIH research and CDC prevention activities. Progress has been great, but much more must be done.

That's why FY 2015 must become a breakthrough year in our collective efforts to stop diabetes. Every 17 seconds, someone in this country is diagnosed with diabetes. Today, 230 Americans with diabetes will undergo an amputation, 120 will enter end-stage kidney disease programs, and 55 will go blind from diabetes. In addition to the horrendous physical toll, diabetes is economically devastating to our country. A 2013 Association report found the **annual cost of diagnosed diabetes has skyrocketed by an astonishing 41% over the last five years** – from $174 billion per year in 2007 to $245 billion in 2012. Despite the escalating cost of diabetes to our nation, the federal investment for diabetes research and programs at the NIH and CDC has not equaled the shocking pace of the diabetes epidemic.

My patients, and individuals with and at risk for diabetes everywhere in this country, deserve a different and brighter future. As the nation's leading non-profit health organization providing diabetes research, information and advocacy, the American Diabetes Association believes the

alarming state of our nation's diabetes epidemic well justifies increased federal funding in FY 2015 for diabetes research and prevention programs.

Background

As the Members of the Committee are aware, diabetes is a chronic disease that impairs the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to 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. Blood glucose levels that are too high or too low (as a result of medication to treat diabetes) can be life threatening in the short term. In the long term, diabetes is the leading cause of kidney failure, new cases of adult-onset blindness, and non-traumatic lower limb amputations – as well as a leading cause of heart disease and stroke. Additionally, an estimated 18 percent of pregnancies are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy placing both mother and baby at risk. In those with prediabetes, blood glucose levels are higher than normal and reducing their risk of developing diabetes it is essential.

The National Institute of Diabetes and Digestive and Kidney Diseases at NIH

For FY 2015 to be a breakthrough year, Congress must support innovative research through NIDDK. While the Association acknowledges the $51 million increase for NIDDK provided in FY 2014, which partially restored the sequestration cuts, there is still no cure for diabetes and every reason to deepen the investment in discoveries at NIDDK that will move us closer to this critical goal. To meet this need, we request funding for NIDDK of $2.066 billion in FY 2015.

NIDDK leads the way in supporting research across the country that moves us closer to a cure and better treatments for diabetes. Thanks to research supported by NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. For example, the continuous glucose monitors and insulin pumps that I and many of my patients use allow us to better manage blood glucose levels – and pave the way to healthier futures.

Examples of NIDDK-funded innovations include: new drug therapies for type 2 diabetes; the advent of modern treatment regimens that have reduced the risk of costly complications like heart disease, stroke, amputation, blindness and kidney disease; and ongoing development of the artificial pancreas, a closed looped system combining continuous glucose monitoring with insulin delivery.

While important progress has been made at NIDDK, the Association's FY 2015 funding request reflects our concern that as the diabetes epidemic has grown, funding for the Institute has lost considerable ground, both due to sequestration and funding not keeping pace with biomedical inflation. As a direct result of sequestration, NIDDK has been unable to fund many promising grant applications over the past several years, severely affecting the prospects for new and improved treatments and, ultimately, the discovery of a cure. Funding of $2.066 billion in FY

2015 will allow the restoration of sequestration cuts enacted in FY 2013, enable NIDDK to support current research projects, and invest in additional studies that hold the promise of stopping diabetes.

The Division of Diabetes Translation at CDC

The prevalence of diabetes has increased dramatically in every state. The federal government's role in coordinating efforts to prevent diabetes and its serious complications has never been more essential. In FY 2014, you and your colleagues recognized this by providing $137.3 million for DDT. On behalf of the Association and the diabetes community, I thank the Members of the Committee for their leadership in providing a long-overdue increase in funding for the CDC's evidence-based, outcomes-focused diabetes programs in FY 2014. We urge the federal investment in DDT programs be funded at $137.3 million in FY 2015.

The mission of DDT is to eliminate the preventable burden of diabetes through research, education, and by translating science into clinical practice. DDT has a proven record of success in the provision of essential information and education to the public, health providers, and patients about the dangers and complications of diabetes. This includes efforts to help those with diabetes manage their disease and avoid devastating complications such as blindness, end-stage kidney disease, and amputation.

The FY 14 funding increase acknowledged the need to invest more funding in diabetes prevention, surveillance, and research programs at DDT. Maintaining these resources in FY 2015 will continue and enhance the cornerstone of DDT's work in all 50 states and Washington, DC through the State Public Health Approaches to Chronic Disease Prevention program (SPHA). The SPHA includes state programming for diabetes, obesity, heart disease and stroke, and school health. Also through SPHA, thirty-two states successfully competed to receive enhanced funding to expand the reach of evidence-based diabetes interventions and conduct more comprehensive evaluation of the program. Funding for DDT also allows the Division to expand its research activities to improve diabetes prevention.

Funding will also ensure additional resources are available for primary and secondary diabetes prevention efforts at the local level, especially in communities hardest hit by diabetes. Additional investment in DDT in FY 2015 will also enable community-based organizations to reduce risk factors for diabetes in populations bearing a disproportionate burden of the disease through two valuable programs: the National Program to Eliminate Diabetes-Related Disparities in Vulnerable Populations and the Native Diabetes Wellness Program, which delivers effective health promotion activities tailored to American Indian/Native Alaskan communities.

The National Diabetes Prevention Program at CDC

As a health care provider on the front lines of the diabetes epidemic, I am alarmed that 79 million Americans have prediabetes and are on the cusp of type 2 diabetes. The National Diabetes Prevention Program is a public-private partnership of community organizations, private insurers, employers, health care organizations, faith-based organizations, and government agencies focused on type 2 diabetes prevention. The program is a national

network of locally-based sites where trained staff provides those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. We urge Congress to provide $20 million for the National Diabetes Prevention Program in FY 2015 to continue its nationwide expansion. The program is a proven means of combating the growing diabetes epidemic.

The National Diabetes Prevention Program began with a successful NIDDK clinical study, which showed that weight loss of 5 to 7 percent of body weight, achieved by reducing calories and increasing physical activity to at least 150 minutes per week, reduced risk of developing type 2 diabetes by 58 percent in people at high risk and by 71 percent for those over 60 years old. Additional translational research was then done, proving the program also works in the less-costly community setting – at a cost of less than $400 per participant.

Currently, over 500 organizations have applied for CDC quality standard recognition, which can lead to third-party reimbursement of the program, ensuring its long-term sustainability. The largest program, run by the Y-USA, has 700 sites in communities in 39 states around the country.

To make FY 2015 a breakthrough year in the quest to stop the diabetes epidemic, funding for the National Diabetes Prevention Program must be increased. This is just the type of program Congress should expand. Additional funding in FY 2015 will allow CDC to further scale this proven approach and support national training programs, public awareness and provider education campaigns, and informed referral networks.

Conclusion

The Association is counting on Congress to significantly invest in diabetes research and prevention programs at NIDDK and DDT, including the National Diabetes Prevention Program. We believe the best way to confront the advancing human and economic pain diabetes exacts on our country is with a deeper investment in cutting-edge medical research and prevention strategies at NIDDK and DDT. We can – and must – change our country's future with regard to this devastating disease and urge the Subcommittee to reflect the explosive growth of this horrendous disease in your FY 2015 appropriations decisions. Thank you for the opportunity to submit this testimony. The Association looks forward to working with you to stop diabetes.

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THE VOICE OF BRAIN INJURY

WRITTEN TESTIMONY

Submitted to
Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Regarding
CDC, HRSA – Department of Health and Human Services
NIDRR – Department of Education

By
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March 28, 2014

Chairman Kingston, Ranking Member DeLauro and members of the Committee,

Thank you for the opportunity to submit this written testimony with regard to the FY 2015 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. BIAA recommends the following funding amounts for the FY 2015 Labor-HHS-Education appropriations bill:

- **$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
- **$12 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

- **$13 million** (+ 1.5 million) for the National Institute on Disability and Rehabilitation Research (NIDRR) TBI Model Systems of Care program in the Department of Education

Among civilians, more than 2.4 million children and adults sustain a traumatic brain injury (TBI) from falls, car crashes, assaults and contact sports each year. Males are more likely than females to sustain brain injuries. Children, teens and seniors are at greatest risk.

The Department of Defense, Defense and Veterans Brain Injury Center (DVBIC) reports that 294,172 service members have sustained traumatic brain injuries since 2000. TBI has been termed the signature injury of the conflicts in Iraq and Afghanistan, and it is possible – indeed, likely – that many more warriors have sustained a brain injury that was misdiagnosed or not diagnosed at all. These brave men and women 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.

Congress has provided minimal funding through the Heath Resources and Services Administration 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 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.

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 2.4 million TBIs occur each year and 5.3 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 $1 million of this request would go to fund CDC's work in this area.

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. 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 $12 million will provide funding necessary to sustain the grants for the 21 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), systems 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 **$13 million** (+ 1.5 million) in FY 2015 for NIDRR's TBI Model Systems of Care program, in order to add two new Collaborative Research Project's. 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.

The Ovarian Cancer National Alliance

House Committee on Appropriations Subcommittee on

Labor, Health and Human Services, Education and Related Agencies

Written Testimony for the Record

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The Ovarian Cancer National Alliance (the Alliance) greatly appreciates the opportunity to submit testimony for the record regarding our fiscal year (FY) 2015 funding recommendations. The FY 2015 programmatic funding levels we are advocating for will help advance the awareness, detection, and treatment of ovarian cancer, the deadliest of gynecologic cancers. Specifically, the Alliance respectfully requests Congress provide **$7.5 million for the Center for Disease Control and Prevention's (CDC) Ovarian Cancer program**. The CDC-led public gynecologic cancer (ovarian, uterine, cervical, vaginal, vulvar) awareness initiatives authorized by Johanna's Law play an integral role in women's cancer education, detection, and prevention. As such, the Alliance respectfully requests Congress appropriate **$5.5 million for Johanna's Law implementation.** Furthermore, to advance and leverage the important ovarian cancer research funded through the National Cancer Institute (NCI) at the National Institutes of Health (NIH), the Alliance respectfully requests Congress allocate **$5.26 billion to NCI, as a portion of $32 billion appropriated to NIH in FY 2015**.

For 17 years, the Alliance has worked to increase awareness of ovarian cancer and advocate for federal investment in research leading to new diagnostics and more effective treatments. As an umbrella organization of 56 state and regional partner member organizations, the Alliance unites the efforts of survivors, caretakers, and health care professionals to bring national attention to ovarian cancer. To advance the interests of women with ovarian cancer, the Alliance advocates at a national level for greater investment in federal research to support the development of an early detection test, improved health care practices and life-saving treatment protocols. The Alliance also educates health care professionals about – and raises public awareness of – the risks and symptoms of ovarian cancer.

Ovarian cancer is a highly deadly disease. According to the American Cancer Society, in 2013, an estimated 22,240 women were diagnosed with ovarian cancer and 14,030 women lost their lives to this terrible disease. A quarter of women diagnosed with ovarian cancer will die within one year of diagnosis and over half of women do not survive five years after diagnosis. Unfortunately, these rates have not changed in nearly 40 years. These grim statistics arise from the fact that there is no early detection test for ovarian cancer; tragically, most cases of ovarian cancer are diagnosed after the disease has already begun to spread and are more difficult to treat effectively. However, if ovarian cancer is caught in the early stages, nearly ninety percent of women survive. As such, it is critical that women and health care providers be aware of the signs and symptoms of ovarian cancer and that valid and reliable early detection tests be developed.

Few treatments for ovarian cancer have been approved by the Food and Drug Administration (FDA). Many FDA approved drugs are platinum-based therapies, to which

cancers readily become resistant if multiple rounds of chemotherapy are needed. Greater than seventy percent of ovarian cancer patients will have a recurrence of disease, underscoring the great need for new and better treatments for ovarian cancer.

For these reasons, we respectfully urge you and your colleagues to support ovarian cancer research, education, and awareness efforts.

CDC Division of Cancer Prevention and Control - Ovarian Cancer

The Ovarian Cancer Line (also known as the Ovarian Cancer Control Initiative) funds public health research of ovarian cancer to better identify women most at risk for developing ovarian cancer, and design risk-reduction and prevention-focused interventions. In FY 2014, CDC's Ovarian Cancer program received $4.75 million to achieve its mission. Some of the projects being supported by those funds include the development of a Continuing Medical Education curriculum on hereditary breast and ovarian cancer to educate physicians about how to identify, screen, and manage high-risk patients; the investigation of ways to improve follow-up care for ovarian cancer patients given that so many experience disease recurrence; and examination of risk factors, treatment disparities, and other influences on survival rates to help identify ways to improve patient outcomes with existing tools and treatments.

With an allocation of $7.5 million in FY 2015, CDC will be able to continue its important public health research, but also expand a pilot initiative integrating ovarian cancer risk assessment, education, and genetic testing into its other cancer-related programs, such as the EARLY Act and the National Breast and Cervical Cancer Early Detection Programs. Given the shared risk between ovarian and breast cancers for individuals with *BRCA* mutations,

integrating breast and ovarian cancer programs in this manner will leverage scarce resources, better coordinate efforts between existing federal programs, create economies of scale and efficiencies with respect to CDC education and awareness programs, and advance complementary efforts to reduce ovarian cancer related deaths.

CDC Division of Cancer Prevention and Control – Johanna's Law

Johanna's Law funds a CDC-led gynecologic cancer awareness campaign, *Inside Knowledge*, which educates women and health care providers about the signs and symptoms of gynecologic cancers. In FY 2014, CDC received $4.85 million for Johanna's Law activities, which include supporting the ongoing creation and dissemination of patient and health care provider awareness campaign materials in English and Spanish and a series of print, radio and television PSAs featuring survivor stories. In 2012, the campaign achieved 1 billion views of its PSAs across media types.

With $5.5 million in FY 2015, CDC will be able to continue to raise awareness of the signs and symptoms of ovarian and other gynecologic cancers, undertake a targeted outreach of its messages to those women with particular disease risk factors, and expand its partnerships with external patient advocacy, health professional, and other stakeholder organizations to leverage scarce resources and amplify their messages.

NCI at NIH

NCI and the NIH fund the majority of ovarian cancer research in the United States and the world. On average, each year, NCI and NIH fund more than $140 million in peer-reviewed,

research grants to researchers at universities and small businesses across the United States. These studies are generating insights into the origins of ovarian cancer and disease progression that help lead to the development of early detection tests and better treatments for ovarian cancer. For example, NIH and NCI investments in basic research led to the understanding of a class of enzymes called PARPs implicated in ovarian cancer. Pharmaceutical companies have built upon these insights to develop PARP inhibitors, a class of drugs holding great promise for ovarian cancer patients.

In addition to the basic research underlying future cures, NCI supports clinical research necessary for translating those ideas into treatments. NCI funding provides critical support to the ovarian cancer Specialized Programs of Research Excellence (SPORES), which facilitate collaborative research studies on the early detection and treatment of ovarian cancer. NCI's clinical trials enterprise plays an essential role in testing the safety and effectiveness of potential treatments for ovarian cancer.

Robust investment in NCI of $5.26 billion, out of a total $32 billion for NIH in FY 2015, is critical to ensuring the next generation of discoveries that will improve the health and well-being of women with – and at-risk for ovarian cancer – as well as all Americans.

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The Alliance maintains a long-standing commitment to working with Congress and other stakeholders to improve the survival rates for women with ovarian cancer through increased research, education and awareness. On behalf of our community of patients, caregivers, and survivors, we thank you for your consideration of our FY 2015 requests and urge you to support the aforementioned federal programs so vital to conquering this horrible disease.

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Testimony of the Pew Children's Dental Campaign
Regarding Fiscal Year 2015 Appropriations
Submitted to the
U.S. House of Representatives Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

On behalf of the Pew Children's Dental Campaign, thank you for the opportunity to submit testimony regarding appropriations for Fiscal Year (FY) 2015. We appreciate the subcommittee's recognition of oral health as a key aspect of overall health and its continued support of programs that expand access to preventive and restorative services through the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC).

The Pew Children's Dental Campaign works at the state and national levels to ensure that more children receive dental care and benefit from evidence-based policies, such as community water fluoridation, dental sealant programs, and expansion of the dental workforce. Since it was established in 2008, our initiative has produced numerous reports evaluating access to care across the 50 states and the District of Columbia, and while we have made significant progress in advancing reforms nationally and in the states, there is still much to be done on this important issue.

Tooth decay affects nearly 60 percent of the nation's children, and, unsurprisingly, its consequences are concentrated disproportionately among low-income children.[i] Dental disease is the most common chronic disease among children in the U.S.—five times more prevalent than asthma, and in a single year, U.S. students may miss as many as 51 million hours of school due to dental health problems.[ii] It causes pain, hampers school performance, and if left untreated can lead to tooth loss and abscesses that spread infection to the blood and brain.[iii]

Lack of access to preventive services and oral health care also imposes a huge cost on states. In 2011, preventable dental conditions were the primary reason for 857, 712 emergency room (ER) visits in the U.S.[iv] In 2010, Florida spent more than $88 million on more than 115,000 hospital ER visits for dental problems and in 2007, 60,000 dental visits to ERs cost the state of Georgia more than $23 million.[vvi] Dental problems can also impact the workforce, causing an estimated 164 million hours of lost work time each year, and can inhibit a person's ability to find a job.[vii] Additionally, a 2008 study of the armed forces found that 52 percent of new recruits were found

to be Class 3 in "dental readiness," meaning they had oral health problems that needed urgent attention and would delay overseas deployment.[viii]

Given the enormous impact of oral health on overall health and the associated social and economic consequences, we respectfully request that the subcommittee consider the following appropriations requests for programs that aim to expand access to care and preventive services for those most in need.

Focusing on prevention

With support from the CDC Division of Oral Health, states can better promote oral health and efficiently administer scarce resources, monitor oral health status and problems, and conduct and evaluate prevention programs through cooperative agreements. 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. The cooperative agreement program also supports state community water fluoridation programs and school-based dental sealant programs, and while funding for this program has been authorized for all 50 states, the Division is currently only able to support 21 states: Colorado, Connecticut, Georgia, Hawaii, Idaho, Iowa, Kansas, Louisiana, Maryland, Michigan, Minnesota, Mississippi, New Hampshire, New York, North Dakota, Rhode Island, South Carolina, Vermont, Virginia, West Virginia, and Wisconsin.

Research shows that community water fluoridation offers one of the greatest returns on investment of any preventive health care strategy. For most cities, every $1 invested in water fluoridation saves $38 in dental treatment costs.[ix] CDC estimates that fluoridated water saves more than $4.6 billion annually in dental costs in the United States,[x] and even more could be saved by expanding coverage to some of the 70 million people who still do not have it.[xi] Dental sealants are also cost-effective; school-based programs can efficiently prevent 60% of decay in the permanent teeth most likely to become decayed during childhood.[xii] We recommend a funding level sufficient to enable all states and the District of Columbia to receive the critical CDC prevention funds, starting with an increase for the coming fiscal year to begin moving toward full funding.

Funding request for FY 2015: $19 million for the CDC Division of Oral Health to expand cooperative agreements to additional states

Addressing the dental access crisis

Pew's 2013 brief, *In Search of Dental Care*, found that roughly 45 million Americans live in dental professional shortage areas, regions that have a scarcity of dentists relative to the population.[xiii] Additionally, in 2011, more than 14 million children enrolled in Medicaid did not receive any dental service, in part due to the low numbers of dentist participation in the Medicaid program.[xiv] The supply of dentists nationally is also likely to shrink in the coming years. The American Dental Association projects that despite the addition of new dental schools and

possible increase in graduates, between 2010 and 2030 the ratio of dentists to Americans will continue to fall due to high numbers of dentists approaching retirement age.[xv]

Many states are expanding scope of practice laws to enable a variety of dental care providers to expand access to care to the underserved, such as dental therapists in Minnesota and Alaska tribal lands, public health hygienists in Kentucky, Maryland, and New Hampshire, and community dental health coordinators in Arizona, California, Montana, New Mexico, Oklahoma, and Wisconsin. A federal demonstration grant program authorized in 2010 but currently unfunded would provide training institutions, community health centers, public hospitals, and other organizations with funding to train these types of providers, all in accordance with state scope of practice laws, and evaluate their impact on access to care.[xvi] Also eligible for funding through this demonstration are programs such as one in California that uses telehealth services to bring care to patients in Head Start centers and nursing homes[xvii] and ER diversion programs that link public hospitals to federally qualified health centers.[xviii]

Pilot efforts to assess how new dental providers can increase access to care are being developed in Oregon, Michigan, Connecticut and Hawaii, and Maine, Kansas, New Mexico, Ohio, and Washington are among the states considering legislation to authorize dental therapists. These providers and programs can increase access at a lower cost to states, and numerous studies have reaffirmed the quality of the services being provided.[xix] These evaluations would not only benefit those states that have authorized alternative providers, but would also provide information to inform policies in the many other states that are struggling to find answers to the challenge of expanding access to the underserved.

HRSA funding request for FY 2015:

- **Removal of the current funding block on existing funding for the Alternative Dental Health Care Provider Demonstration Grants, Section 340G-1 of the Public Health Service Act, and an appropriation of $10 million to initiate the program**
- **$32 million for Title VII program grants to expand and educate the dental workforce**

By making targeted federal investments in effective policy approaches, the subcommittee can enable states to sustain programs that prevent the pain, missed school hours and long-term health and economic consequences of untreated dental disease. A handful of states are leading the way, but all states can and must do more to ensure access to dental care for those who need it most. Thank you for your consideration of this testimony.

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THE **AIDS** INSTITUTE

WRITTEN STATEMENT OF
CARL SCHMID, DEPUTY EXECUTIVE DIRECTOR, THE AIDS INSTITUTE
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION,
AND RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS
MARCH 28, 2014

Dear Chairman Kingston and Members of the Subcommittee:

The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer comments in support of critical HIV/AIDS and hepatitis programs as part of the FY2015 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for supporting these programs over the years, and hope 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. According to the CDC, in the U.S. over 636,000 people have died of AIDS and there are 50,000 new infections each year. A record 1.1 million people in the U.S. are living with HIV. Persons of minority races and ethnicities are disproportionately affected. African Americans, who make up just 12 percent of the population, account for 44 percent of new infections. HIV/AIDS disproportionately affects low income people; nearly 90 percent of Ryan White Program clients have a household income of less than 200 percent of the Federal Poverty Level.

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 domestic HIV/AIDS efforts

are funded through this Subcommittee. We are keenly aware of current budget constraints and competing interests for limited dollars, but programs that prevent and treat HIV are inherently in the federal interest as they protect the public health against a highly infectious virus. If left unaddressed, it will certainly lead to increased infections, more deaths, and higher health costs.

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease if people have access to consistent and affordable health care and medications. Through prevention, care and treatment, and research we now have the ability to actually end AIDS. In 2011, a ground-breaking clinical trial (HPTN 052) – named the scientific breakthrough of the year by *Science* magazine – found that HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96 percent – proving that HIV treatment is also HIV prevention. In order to realize these benefits, people with HIV must be diagnosed through testing, and linked to and retained in care and treatment.

We also have a National HIV/AIDS Strategy that sets clear goals and priorities, and brings the federal agencies addressing HIV together to ensure resources are well coordinated.

The Ryan White Program

The Ryan White HIV/AIDS Program provides some level of medical care, drug treatment, and support services to approximately 554,000 low-income, uninsured, and underinsured individuals with HIV/AIDS. With people living longer and continued new diagnoses, the demands on the program continue to grow and many needs remain unmet. According to the CDC, only 37 percent of people living with HIV in the U.S. are retained in HIV care, only 33 percent have been prescribed antiretroviral treatment, and only 25 percent are virally suppressed. We have a long way to go before we can realize the dream of an AIDS-free generation. With continued funding we can improve these numbers and health outcomes.

The AIDS Drug Assistance Program (ADAP), one component of the Ryan White Program, provides states with funds to pay for medications for over 200,000 people. Over the last couple of years, as more infections were identified due to increased HIV testing and people lost their jobs and health insurance, demand on the program far outpaced its budget. This led to ADAP wait lists of 9,300 people. We are thankful that President Obama and Congress allocated additional funds, which when combined with assistance from pharmaceutical companies has virtually eliminated the wait list. With inadequate funding that could all change.

We urge you to ensure that ADAP and the rest of the Ryan White Program receive adequate funding to keep up with the growing demand. According to NASTAD, enrollment in ADAP increased by 8 percent between FY2012 and FY2013, and utilization reached its highest level ever. With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program.

As the Affordable Care Act (ACA) is implemented, there will be expanded opportunities for health care coverage for some Ryan White clients. While it will result in some cost shifting for medications and primary care, it will never be a substitute for the Ryan White Program. Over 70 percent of Ryan White Program clients today have some sort of insurance coverage, mostly through traditional Medicaid and Medicare. Their coverage will not change with health reform; the Ryan White Program will be needed as it is today. The Medicaid expansion is a state option and not all states are moving forward with it at this time. As ACA is implemented, benefits will differ from state to state and there will be many gaps that will have to be filled by the Ryan White Program. Plans will not offer all of the comprehensive essential support services, such as case management, transportation, and nutritional services, that are needed to ensure retention in medical care and adherence to drug treatment. This approach of coordinated, comprehensive, and

culturally competent care leads to better health outcomes. Therefore, the Ryan White Program, while it may need to change in the future, must continue and must be adequately funded.

The AIDS Institute urges the Committee to reject the President's budget proposal to eliminate dedicated funding for Part D of the Ryan White Program and transfer it to Part C. Part D serves women, infants, children, and youth with HIV/AIDS and is a well-established system of care that has worked since 1988 in nearly eliminating perinatal infection and providing medical care and family-centered support that helps ensure these vulnerable populations remain in care and adherent to their medications. While changes to the structure of the Ryan White Program might be needed in the future, it should not be done through the appropriations process and not without community input.

CDC HIV Prevention

As a Nation, we must do more to prevent new infections, but we only allocate 3 percent of our HIV/AIDS spending towards prevention. All the care and treatments costs would be saved if we did not have the infections in the first place. Preventing just one infection would save $402,000 in future lifetime medical costs. Preventing all the new 50,000 cases in just one year would translate into an astounding $20 billion saved in lifetime medical costs.

With more people living with HIV than ever before, there are greater chances of HIV transmission. The CDC and its grantees have been doing their best with limited resources to keep the number of infections stable, but that is not good enough. It is focusing resources on those populations and communities most impacted by HIV and investing in those programs that will prevent the most number of infections. One group in particular that needs additional study and resources is young black gay men, who experienced a 38 percent increase in new infections from 2008-2010.

With over 200,000 people living with HIV who are unaware of their infection, the CDC is also focused on increased testing programs. Testing people early and linking them to care and treatment is critical not only for their own health outcomes but also in preventing new infections.

The CDC estimates that in 2010, 26 percent of all new HIV infections occurred among youth ages 13 to 24. Nearly 75 percent of those infections were among young gay men. Clearly, we must do a better job of educating the youth of our Nation, including gay youth, about HIV. Adequately funding the HIV Division of Adolescent and School Health (DASH) will help address this critical need.

CDC Viral Hepatitis Prevention

Given that more than 5.3 million people in the U.S. are living with hepatitis B and/or C and 65-75% of them are undiagnosed, funding for the Hepatitis Prevention Division must be increased. The current amount of only $29 million is far too small to conduct testing, surveillance, and other hepatitis prevention and educational programs for the entire country.

HIV/AIDS Research at the National Institutes of Health (NIH)

While we have made great strides in the area of HIV/AIDS, there is still a long way to go. Continued research at the NIH is necessary to learn more about the disease and to develop new treatments and prevention tools. Work continues on vaccine research and we look forward to an eventual cure.

Again, we thank you for your continued support of these programs critical to so many individuals and communities nationwide. We have made great progress, but we are still far from achieving our goal of an AIDS-free generation. We now have the tools, but we need continued leadership and the necessary resources to realize our goal. Thank you.

To: House Appropriations Committee

From: William Smith, Executive Director, National Coalition of STD Directors

CDC's Division of STD Prevention Funding History	
FY2015 Recommendation*:	$211.199 million*
FY 2015 President's Budget:	$157.719 million+
FY2014 Funding Level:	$157.719 million
FY2013 Funding Level:	$154.861 million
FY2012 Funding Level:	$163 million

**$53.48 million increase*

+This includes $9.2 million from the Working Capital Fund (WCF). WCF funding has been added to all other funding levels to make them comparable to the FY15 President's Budget.

On behalf of the members of the National Coalition of STD Directors, who represent sexually transmitted disease (STD) programs in all 65 directly-funded project areas of the Centers for Disease Control and Prevention (CDC)--all fifty states, eight cities and seven U.S. territories-- I am writing to request an additional $53.48 million for the Division of STD Prevention in fiscal year (FY) 2015 funding. The Division of STD Prevention is part of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the CDC.

STDs remain major epidemics in the United States. Each year, there are almost 20 million new cases of STDs, approximately half of which go undiagnosed and untreated, giving the United States the highest STD rate in the industrialized world. These new STDs cost the U.S. health care system $16 billion every year—and cost individuals even more in immediate and life-long health consequences, including infertility, higher risk of acquiring HIV, and certain cancers.

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The CDC's Division of STD Prevention (DSTDP) guides national efforts to prevent and control STDs and invests most of its resources in state, territorial, and large city health departments. CDC/DSTDP needs additional federal resources to reverse the alarming and costly trends of STDs. In fiscal year 2015 funding, please support an increase of $53.48 million to support the prevention of STDs and their complications and to ensure those on the front lines of STD prevention have funding to prepare for the immerging threat of drug-resistant gonorrhea.

Gonorrhea is the second most commonly reported communicable disease in the United States. Gonorrhea has developed resistance to every class of antibiotics recommended for its treatment; we are now on our last line of defense to treat this disease that is a major cause of pelvic inflammatory disease, ectopic pregnancy, infertility and can facilitate HIV transmission. Given the current trajectory of this disease, the question is not *if* gonorrhea will develop resistance to all drugs designed to treat it, but *when.*

While this issue poses grave concerns for all sexually-active people, drug-resistant gonorrhea will hit certain populations harder than others including men who have sex with men (MSM), blacks, and young people:

- Men who have sex with men (MSM) already have the highest rates of gonorrhea resistance across the country.
- The rate of gonorrhea among blacks is 14.9 times the rate of gonorrhea among whites.
- Young people aged 24 and younger account for 58% of the new gonorrhea cases every year.

Untreated gonorrhea is a disaster for public health and HIV prevention. In 2013, the CDC released Antibiotic Resistance Threats in the United States, 2013, its first-ever snapshot of the burden and threats posed by the antibiotic-resistant germs having the most impact on human

health and in this report named drug-resistant gonorrhea one of three "urgent" threats, the highest level in this report. If drug-resistant gonorrhea becomes widespread not only would it dramatically increase gonorrhea rates, the broader public health impact during a 10-year period would be devastating. It is estimated that it would lead to 75,000 additional cases of pelvic inflammatory disease (a major cause of infertility), 15,000 cases of epididymitis, and hundreds of additional HIV cases.

The direct medical costs of drug-resistant gonorrhea are estimated to be $235 million 10 years after onset of drug resistance. In reality, however, the real costs of gonorrhea resistance are likely to be much higher—this estimate does not account for increased susceptibility monitoring, additional provider education, case management, and the need for additional courses of antibiotics and follow-up.

The current public health infrastructure has been continually strained by budget reductions both at the federal and state level and is currently unable to prepare as necessary for the arrival of untreatable gonorrhea. STD programs have been doing more with less for years and it can no longer continue. The system cannot respond to additional demands and threats with the same level of funding; additional funding is desperately needed.

We acknowledge the political and budgetary climate in which Congress finds itself. But the reality is that soon we will have yet another un-treatable STD on our hands. Investments made now can help respond to future public health emergencies and delay a costly untreatable gonorrhea epidemic.

This request outlines what state and local health departments, as well as on-the-ground partners, need to effectively respond to the growing resistance of gonorrhea to the last drug shown to treat it. It outlines the needs in five distinct areas:

- Proper Diagnosis and Treatment: $11.38 million

  While we may not be able to completely avoid the arrival of drug-resistant gonorrhea, we can decrease the burden of gonorrhea currently seen in our country, thereby reducing the response needed when resistant strains are identified. Scaled up screening programs are needed, as well as ensuring the recently-updated CDC screening and treatment guidelines for gonorrhea are being followed by private providers.

- Surveillance and Increased Lab Capacity: $6.1 million

  CDC currently conducts surveillance for gonorrhea resistance through the Gonococcal Isolate Surveillance Project (GISP), a sentinel surveillance that collects data from a group of STD clinics around the country. GISP has successfully detects trends in resistance, provides prevalence data and directly informs CDC treatment recommendations for gonorrhea. Using the current GISP system as a model, this funding would establish "mini-GISP" models across the country to ensure we receive not only more gonorrhea resistance data but also data in real time. This funding will also increase lab capacity across the country, a key weakness in our response to multi-drug resistant gonorrhea.

- Disease Intervention Specialists: $19.5 million

  Disease Intervention Specialists (DIS) are a workforce that is the underpinning of all STD and HIV health department programs. Vital to health departments across the country, DIS personnel conduct voluntary interviews with patients to obtain the names and contact information of their sexual partner(s) and then use that information to contact a patient's sexual partner(s) and inform them of their potential exposure to an STD or HIV. To get a better handle on the gonorrhea disease burden ahead of multi-drug resistant gonorrhea, state

and local health departments need additional DIS to identify partners of possible exposure to gonorrhea and link them to care.

- Evidence-Based Interventions: $10 million

  As treatment resistance draws closer, we need to reduce our existing gonorrhea disease burden. Especially given the asymptomatic nature of many gonorrhea infections, the more gonorrhea there is in a community, the more likely it is to spread, and that fact will only be compounded with the arrival of treatment-resistant strains. Funded is need to scale-up existing evidence-based interventions, particularly for populations most at risk, as well as developing additional interventions.

- Education and Awareness: $6.5 million

  Additional funding is needed to increase STD education and awareness efforts across the country. The public must be better educated on the reality of the rise of multi-drug resistant gonorrhea and what it means for the current and future treatment of gonorrhea.

In totality, this request will allow for state and local health departments to implement CDC's Cephalosporin-Resistant Gonorrhea Response Plan. Additional information on this request can be found on NCSD's website at: www.ncsddc.org/fundingforgonorrhearesistance.

We do not want to have another HIV-like epidemic on our hands, where an STD is not treatable. Investments made now can help us better understanding where resistant gonorrhea will likely occur and allow us to respond when it does to minimize its effect. Please support an increase of $53.48 million for the Division of STD Prevention in FY2015.

For more information about this funding request or STD prevention in general, please contact the National Coalition of STD Director's Director of Policy and Communications, Stephanie Arnold Pang at sarnold@ncsddc.org or 202-842-4660.

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March 28, 2014

Testimony in support of the State Paid Leave Fund
Submitted to the U.S. House of Representatives Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education and Related Agencies
Gayle L. Goldin, State Senator, Providence, Rhode Island

As the legislative champion of Temporary Caregiver Insurance, Rhode Island's new paid family leave fund, I respectfully urge the Committee on Appropriations to include the State Paid Leave Fund, administered through the Department of Labor, in the Fiscal Year 2015 Labor, Health and Human Services and Education bill. The bill should include the $105 million funding proposed in the President's budget. The State Paid Leave Fund would create a competitive federal grant fund designed to spur innovation among states interested in creating family and medical leave insurance (FMLI) programs, as well as those with established FMLI programs, and has the potential to help millions of American families, including thousands here in Rhode Island, maintain economic security.

Last year, Rhode Island passed historic legislation, making our state the third in the country with paid family leave and the first to do so with job protection, ensuring that nearly 80 percent of workers in Rhode Island can now access paid family leave.

At some point in their working lives, almost all Americans will need to take time off to care for a new baby or adopted child, an ailing child or parent, or their own health. The Family and Medical Leave Act - the only federal law designed to help working people meet the dual demands of job and family - leaves out 40 percent of the workforce <http://www.dol.gov/asp/evaluation/fmla/fmla2012.htm> and guarantees only unpaid leave, which millions cannot afford to take. And only 12 percent of the U.S. workers currently have access to paid family leave through their employers. That means millions of workers who develop serious health conditions, have seriously ill family members or become parents are forced to choose between what is best for them and their families and income they need to cover basic expenses.

Family and medical leave insurance programs at the state level allow workers to pay a small portion of their wages each week for the guarantee that when they need it, they can receive a percentage of their wages while they have to take extended family or medical leave from work. These programs help working families stay afloat when they need time off to care for an ill family member, a new baby or their own health.

As a state senator, I champion paid family leave because I know it's good for our families, good for business, and good for our economy.

That's why there is broad support among the business community for paid family and medical leave programs. Businesses understand it's good for their bottom line. California employers report that the program has had a neutral or positive effect on employee productivity <http://www.cepr.net/documents/publications/paid-family-leave-1-2011.pdf> , profitability, and turnover, and most employers coordinate their own benefits with the state's PFL program. A 2011 study of California's FMLI program estimated that it would save employers $89 million a year <http://digitalcommons.law.ggu.edu/cgi/viewcontent.cgi?article=2036&context=ggulrev> . A recent Rutgers study shows that New Jersey <http://news.rutgers.edu/medrel/news-releases/2012/01/rutgers-study-finds-20120118> 's FMLI program has saved businesses money by improving employee retention, decreasing turnover costs, and improving productivity. At the same time, businesses know that when people have money in their pockets, they can continue to go grocery shopping and, in doing so, keeps our grocery stores open and their workers employed.

A federal grant program would help states with one-time start-up costs to develop and implement successful family and medical leave insurance programs that are so needed across the country. Once these insurance programs are up and running they become self-sustaining. Without this federal support, the initial capital needed to design and launch these programs would continue to act as a roadblock, despite broad public support.

This fund would benefit both states considering a family leave and medical insurance program and states with an existing FMLI program. States with established FMLI programs could apply for grants to increase awareness about and utilization of the program by conducting outreach to ensure eligible workers who have been paying into the program are accessing it when they need it. For many states considering programs, access to competitive federal grants that help defray the one-time costs of designing and launching these insurance programs would provide a compelling incentive to states to innovate. In the case of the SPLF, a modest investment at the federal level would translate to significant impact for millions of families' economic security.

Rhode Island has already seen nearly 1,000 applications for Temporary Caregiver Insurance, but with funding from the State Paid Family Leave Fund, we could do broader outreach, staff telephone lines, develop easier application process, and ensure all employees, employers, and health care professionals understand how our new law works.

In sum, there is tremendous support across the country for creating a new State Paid Leave Fund. Nearly a dozen states, including Rhode Island, could immediately benefit from federal funds made available through a competitive grant program. I urge you to pass a budget bill with $105 million allocated for the State Paid Leave Fund to help states like Rhode Island with programs that benefit working families, businesses, and the local economy.

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The Neurofibromatosis (NF) Network

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 research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. We respectfully request that you include the following report language on NF research at the National Institutes of Health within your Fiscal Year 2015 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF] *– The Committee supports efforts to increase funding and resources for NF research and treatment at multiple NIH Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair, learning disabilities and attention deficit disorders. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2 basic and clinical research.*

On behalf of the Neurofibromatosis (NF) Network, a national organization 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 and conditions linked to NF such as cancer, brain tumors, heart disease, memory loss, and learning disabilities. Thanks in large measure to this Subcommittee's strong 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.

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, pain, blindness, brain tumors, cancer, and even death. In addition, approximately one-half of children with NF suffer from learning disabilities. NF is the most common neurological disorder caused by a single gene and is more common than Muscular Dystrophy and Cystic Fibrosis combined. There are three types of NF: NF1, which is more common, NF2, which initially involves tumors causing deafness and balance problems, and Schwannomatosis, the hallmark of which is severe pain. 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.

Researchers have determined that NF is closely linked to heart disease, learning disabilities, memory loss, cancer, brain tumors, and other disorders including deafness, blindness and orthopedic disorders, primarily because NF regulates important pathways common to these

disorders such as the RAS, cAMP and PAK pathways. Research on NF therefore stands to benefit millions of Americans:

Learning Disabilities/Behavioral and Brain Function - Learning disabilities affect two-thirds of people with NF1, ranging from mild to severe, and including attention and social behavior deficits. Learning disabilities impact the quality of life for those with NF1 more than tumors or any other clinical feature. In recent years, research has revealed common threads between NF1 learning disabilities, autism and other related disabilities.

Bone Repair - At least a quarter of children with NF1 have abnormal bone growth in any part of the skeleton. In the legs, the long bones are weak, prone to fracture and unable to heal properly; this can require amputation at a young age. Adults with NF1 also have low bone mineral density, placing them at risk of skeletal weakness and injury. Research currently being done to understand bone biology and repair will pave the way for new strategies to enhancing bone health and facilitating repair.

Pain Management - Severe pain is a central feature of Schwannomatosis, and significantly impacts quality of life. Understanding what causes pain, and how it could be treated, has been a fast-moving area of NF research over the past few years. Pain management is a challenging area of research and new approaches are highly sought after.

Nerve Regeneration - NF often requires surgical removal of nerve tumors, which can lead to nerve paralysis and loss of function. Understanding the changes that occur in a nerve after

surgery, and how it might be regenerated and functionally restored, will have significant quality of life value for affected individuals. Light-based therapy is being tested to dissect nerves in surgery of tumor removal. If successful it could have applications for treating nerve damage and scarring after injury, thereby aiding repair and functional restoration.

Wound Healing, Inflammation and Blood Vessel Growth - Wound healing requires new blood vessel growth and tissue inflammation. Mast cells, important players in NF1 tumor growth, are critical mediators of inflammation, and they must be quelled and regulated in order to facilitate healing. Researchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling, resulting in slower tumor growth. As researchers learn more about blocking mast cell signals in NF, this research can be translated to the management of mast cells in wound healing.

New Cancer Treatments - NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70% of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. One of these tumor types is malignant peripheral nerve sheath tumor (MPNST), a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million

Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from $3 million in FY1990 to an estimated $18 million in FY2014. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that the NIH will continue to build on the successes of this program by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

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.

Testimony of **Daniel Paul Perez, President & CEO, FSH Society** phone: (781) 275-7781, e-mail: daniel.perez@fshsociety.org before the United States House Appropriations Committee, Subcommittee on Labor, Health and Human Services, and Education on the subject of **$18 million FY2015 Appropriations for U.S. DHHS National Institutes of Health (NIH) Research Programs on Facioscapulohumeral Muscular dystrophy (FSHD)** March 28, 2014

Honorable Chairmen Rogers and Ranking Member Lowey, thank you for the opportunity to submit this testimony. Facioscapulohumeral muscular dystrophy (FSHD), is one of the most common adult muscular dystrophies with a prevalence of 1:15,000–1:20,000[1,2]. For a half-million men, women, and children worldwide the major consequence of inheriting this genetic form of muscular dystrophy is a lifelong progressive loss of all skeletal muscles. FSHD is a crippling and life shortening disease. No one is immune. It is both genetically and spontaneously transmitted to children. It can affect multiple generations and entire families.

With FSHD there is a loss of muscle strength that ranges between one and four percent a year during a lifetime. In terms of functional impairment, 20 percent of FSHD-affected individuals over age fifty will require the use of a wheelchair. FSHD also has very specific non-muscular manifestations; hearing-loss, restrictive lung disease, supraventricular arrhythmias (rare), and retinal vasculopathy. 95% of individuals with FSHD have the FSHD1 (FSHD1A) genetic variation -- caused by the contraction of DNA macrosatellite repeat units, termed D4Z4 repeats, on chromosome 4, leading to the release of transcriptional repression of a retrogene (DUX4) believed to be associated with the cause of disease. Of the 5% of FSHD individuals remaining, 80% of those are the FSHD2 (FSHD1B) genetic variation -- caused by mutations in the SMCHD1 gene on chromosome 18 that helps to maintain the structure of the D4Z4 repeats on the long arm of chromosome 4.

The National Institutes of Health (NIH) is the principal source of funding of research on FSHD currently at the $5 million level. For nearly two decades, this Committee has supported the incremental growth in funding for FSHD research. I am pleased to report that this modest

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investment has produced huge scientific returns.

1. Congress has made a major difference in muscular dystrophy. I have testified many times before Congress, nearly fifty. When I first testified, we did not know the mechanism of this disease. Now we do. When I first testified, we assumed that FSHD was a rare form of muscular dystrophy. Now we understand it to be one of the most prevalent forms of muscle disease, if not the most prevalent muscle disease based on new ways of evaluating the disease clinically within families. Congress is responsible for this success, through its sustaining support of the NIH and the enactment of the Muscular Dystrophy CARE Act. We are aware that MD Care Act does not set the amount of spending on FSHD or the other dystrophies at the NIH and we recognize that funding levels are determined in the appropriations process and the numbers of grant applications received and funded by the NIH on FSHD. Even though it is a technically separate legislative process, the reauthorization of the MD Care Act does raise the visibility of all the muscular dystrophies which can be of help in the appropriations process – and we thank you for your support of the MD Care Act. Further, we recognize and feel at this time in FSHD research that there are additional efforts and pathways that Congress can request and the NIH can enact to increase the amount of research funding on FSHD in the NIH portfolio that neither increases the NIH budget required nor takes money from another area of research.

2. Quantum leaps in our understanding of FSHD have occurred in past three and a half years. The past three and a half years have seen remarkable contributions made by researchers funded by NIH.

- On August 19, 2010, American and Dutch researchers published a paper which dramatically expanded our understanding of the mechanism of FSHD.[3] A front page story in the New York Times quoted the NIH Director Dr. Francis Collins saying, "If we were thinking of a collection of the genome's greatest hits, this would go on the list."[4]
- Two months later, another paper was published that made a second critical advance in determining the cause of FSHD.[5] The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development.

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- On January 17, 2012, an international team of researchers based out of Seattle discovered a stabilized form of a normally suppressed gene called DUX4 required to develop chromosome 4 linked FSHD.[6]
- Six months later, another high profile paper produced by a Senator Paul A. Wellstone Cooperative Research Center of the NIH, used sufficiently "powered" large collections of genetically matched FSHD cell lines generated by the NIH center that are both unique in scope and shared with all researchers worldwide, to improve on the Seattle group's finding by postulating that DUX4-fl expression is necessary but not sufficient by itself for FSHD muscle pathology.[7] This work was also supported by a NIH cooperative research center grant mandated by MD CARE Act.
- On July 13, 2012, a team of researchers from the, United States, Netherlands and France identified mutations in a gene causing 80% of another form of FSHD. This paper furthers our understanding of the molecular pathophysiology of FSHD. This work too was supported in part by a program project grant from NIH.[8]
- In 2013 and continuing into 2014, papers have been published clearly documenting functional impairment in FSHD, clinical and genetic features of hearing loss FSHD, restrictive lung disease and respiratory insufficiency, Coats syndrome and vision loss in FSHD, high-throughput screening that identify inhibitors of DUX4-induced myoblast toxicity, better definition of epigenetic features of FSHD, Pain and FSHD, MRI/MRS studies, biomarkers for FSHD, the demonstration that although the transcription of the toxic protein DUX4 occurs in only a limited number of nuclei, the resulting protein diffuses into nearby nuclei within the myotubes, thus spreading aberrant gene expression throughout a muscle, to name a few.

Many of these researchers have started their efforts in FSHD with seed funding from the FSH Society and have received continued support from the FSH Society, the NIH, and the Muscular Dystrophy Association and other partners.

3. Remarkable progress in FSHD research and the need to keep moving forward. Last October, nearly 100 researchers from around the world gathered under the direction of Massachusetts Institute of Technology professor, David Housman, PhD, Chair of the FSH Society's Scientific Advisory Board, at the David H. Koch Center for Integrative Cancer Research on the campus of M.I.T. for the annual FSH Society International Research Consortium meeting; there was a palpable feeling of FSHD research having "arrived" in the big time. The general discussion of day two covered four major areas. With respect to the first area, called **DUX4**, the unanimous conclusion of the general discussion was that over-expression of the toxic transcription factor Dux4 is at the root of FSHD1 and FSHD2 and that DUX4 expression is necessary but not always sufficient to cause FSHD. Research should focus on upstream and downstream molecular pathways and mechanisms as they form the most plausible intervention targets. The group also discussed needs and priorities in three additional areas: **disease models,**

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intervention, clinical studies and trial readiness. The priorities stated for 2014, at the October 21-22, 2013, FSH Society FSHD IRC meetings are as follows: [9]

- The DUX4 interactome
- Understanding DUX4 manifestation and variation
- Additional genetic heterogeneity; non-FSHD1 and FSHD2
- Disease models
- Well documented Natural history with reliable endpoints; modulating mechanisms/genes
- Increasing data depth of patient databases with extensive (follow-up) clinical data
- Prepare for clinical trials: reliable and meaningful outcome measures; with access to discreet patient populations and disease mechanism of action classes.
- Therapy; proof-of-principle experiments
- Focus on translational research; from clinic to bench and back
- Understanding pathophysiology of FSHD: connection to DUX4, heterogeneity, asymmetry, role of inflammation; infiltrates and etiology

Given the recent developments, there is a need to ramp up the preclinical enterprise and build/organize infrastructure needed to conduct clinical trials. Our immediate priorities should be to confirm the new hypotheses and targets. We need to be prepared for this new era in the science of FSHD. 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 thinking about and treating human disease.

4. NIH Funding for Muscular Dystrophy. Mr. Chairman, these major advances in scientific understanding and epidemiological surveillance are not free. They come at a cost. Since Congress passed the MD CARE Act, research funding at NIH for muscular dystrophy has increased 4-fold. While FSHD research funding has increased 12-fold during this period, the level of funding is still anemic and, for FSHD, has been astonishingly flat for the past six years.

FSHD Research Dollars (in millions) & FSHD as a Percentage of Total NIH Muscular Dystrophy Funding
Sources: NIH/OD Budget Office & NIH OCPL & NIH RCDC RePORT
(e = estimate)

Fiscal Year	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**2014e**	**2015e**
All MD ($ millions)	$39.1	$38.7	$39.5	$39.9	$47.2	$56	$83	$86	$75	$75	$76	$78	$78
FSHD ($ millions)	$1.5	$2.2	$2.0	$1.7	$3	$3	$5	$6	$6	$5	$5	$6	$6
FSHD (% total MD)	4%	6%	5%	4%	5%	5%	6%	7%	8%	7%	7%	8%	8%

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Despite the great success of the past three and a half years in the science of FSHD brought about by Congress we are concerned that under the current funding environment that new research projects will not be funded or existing programs will not be renewed. We have conveyed to the NIH leadership at the Office of the Director, NIAMS, NINDS, NICHD, NHLBI and the Executive Secretary of the MDCC our grave concern that FSHD research is way too under-represented in the NIH portfolio and needs a proactive effort on the part of NIH.

We request for FY2015, a tripling of the NIH FSHD research portfolio to $18 million or a level of approximately 20% of the total muscular dystrophy funding at NIH. This will allow an expansion of basic research awards, expansion of post-doctoral and clinical training fellowships, dedicated centers to design and conduct clinical trials on FSHD and more U.S. DHHS NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers.

We are aware of the great pressures on the federal budget, but NIH can easily help increase its portfolio on FSHD by issuing one or more of the following on FSHD: Program Announcement (PA), Program Announcement (PA) with set-aside (PAS), PA with special review (PAR), or PA with set-aside special review (PAR/S). A request for applications (RFA) on FSHD would certainly help for the very short-term given the breakneck speed of discovery in FSHD, and the case can be made to NIH leadership . These are easy ways for NIH to convey to researchers that it has an interest in funding research in FSHD. Additionally, NIH could issue announcements with special receipt dates – this too would send a positive signal to the research community. There are no quotas on peer-reviewed research above pay line at the NIH, and NIH can help by issuing written announcements that efforts invested in writing FSHD grant applications will be met with interest. This is the time to fully and expeditiously exploit the advances for which the American taxpayer has paid. Thank you for this opportunity to testify before your committee.

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Chairman Kingston, 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 (GPEI) is an unprecedented model of cooperation among national governments, civil society and UN agencies working together to reach the most vulnerable children through the safe, cost-effective public health intervention of polio immunization. We appeal to this Subcommittee for continued leadership to ensure we seize the opportunity to conquer polio once and for all. Rotary International strongly supports the President's 2015 request of $161 million for the polio eradication activities of the CDC to enable full implementation of the polio eradication strategies and innovations outlined in the *Polio Eradication and Endgame Strategic Plan (2013-2018).*

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Significant strides were made in 2013 toward stopping transmission of polio. Thanks to this committee's leadership in appropriating funds for the polio eradication activities of the CDC:

- India was certified polio free in February 2014, following three years with no cases of polio. The entire Southeast Asia region was certified polio free on 27 March 2014.
- Eradication efforts have led to more than a 99% decrease in cases since the launch of the GPEI in 1988.
- The number of polio cases in the endemic countries was 40% lower in 2013 than in 2012 (160 vs. 217). Afghanistan and Nigeria each had less than half the number of cases in 2013 that they had in 2012.
- Pakistan is now considered to be the only country in the world with uncontrolled transmission of wild polio and as of 20 March, accounts for more than 75% of polio cases in 2014.

- Outbreaks in the Horn of Africa and Syria accounted for roughly 60% of all cases in 2013. These outbreaks underscore the risk to polio-free countries until the wild poliovirus has been eradicated in the remaining places where it persists.
- Incidence of type 3 polio is at historically low levels. There have been no cases of type 3 polio since November 2012.
- Lack of access to children in insecure areas continues to hamper progress. In Pakistan alone, more than 50 health workers and security personnel assigned to protect them have been killed in targeted attacks since November of 2012. Insecurity /inability to access large populations is now a key factor in all endemic transmission zones and is also a factor in outbreak areas (Syria, Horn of Africa).

The *Polio Eradication and Endgame Strategic Plan (2013-2018)* launched in 2013 lays out the strategies for the certification of the eradication of wild poliovirus by 2018 at a total global cost of US$5.5 billion. This new plans builds on the lessons learned from the successful eradication of polio to date and the substantial advances in technology in 2012. The timely availability of funds remains essential to the achievement of a polio free world. The United States has been the leading public sector donor to the Global Polio Eradication Initiative. Members of US Rotary clubs appreciate the United States' generous support and recognize increased funding provided by Congress in FY2014 to ensure the GPEI can fully implement the plan. Rotarians are committed to continuing their own fundraising for the program until the world is certified polio free. Rotarians will also continue to advocate support from the public and other governments, both polio free and polio affected, to support the successful execution of the *Strategic Plan.* The ongoing support of donor countries, like the United States, is essential to assure the necessary

human and financial resources are made available to polio-endemic and at risk countries to certify the world polio free by the end of 2018.

THE ROLE OF ROTARY INTERNATIONAL

Rotary International, a global association of more than 34,000 Rotary clubs in more than 170 countries with a membership of over 1.2 million business and professional leaders (more than 345,000 of which are in the U.S.), has been committed to battling polio since 1985. Rotary International has contributed more than US$1.2 billion toward a polio free world – representing the largest contribution by an international service organization to a public health initiative ever. 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 Foundation, the American Academy of Pediatrics, the Task Force for Global Health, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in thanking you for your support of the GPEI.

THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's increased support of CDC's polio eradication activities to support full implementation of the *Strategic Plan*. The United States is the leader among donor nations in the drive to eradicate this crippling disease. CDC is using the increased Congressional support provided in FY 2014 to:

- **Build capacity in Nigeria.** Increased investment in Nigeria will serve to establish and broaden environmental surveillance; strengthen traditional AFP surveillance, scale up the National Stop Transmission of Polio Program (N-STOP) in Kano and other high risk polio states to ensure broad coverage at the Local Government Authority Level, trapping poliovirus in its remaining reservoirs in Northern Nigeria.

- **Build capacity in Pakistan.** Increased investment in Pakistan will focus on training and placing local personnel to strengthen the program in areas where access is possible.
- **Provide essential technical assistance in Afghanistan.** The investment in Afghanistan will support two staff members in country.
- **Laboratory Surveillance:** Investment with CDC's Polio Global Reference Lab will allow the recruitment of additional staff, training for country and regional labs, essential IPV research, and expansion of environmental surveillance capabilities in the field. CDC provides technical and programmatic assistance to the global polio laboratory network through the Polio Laboratory in CDC's Division of Viral Diseases. CDC's labs provide critical diagnostic services and genomic sequencing of polioviruses to help guide disease control efforts. CDC will continue to serve as the global reference laboratory, while expanding environmental surveillance in countries to serve as a "safety measure" to detect any polioviruses circulating in areas without cases.
- **Vaccine Purchase:** CDC funds are being used to purchase oral polio vaccine to immunize children against polio.
- **Vaccine Operations & Social Mobilization.** CDC, through its cooperative agreement with WHO, provides funding for immunization activities in high risk and polio infected countries. CDC funding is essential to supporting the supplemental immunization activities that both stop existing outbreaks and prevent new outbreaks. CDC collaborates closely with UNICEF and provides critical support on analysis and use of campaign results to identify and address reasons why children are missed and address vaccine hesitancy concerns.

- **Immunization Systems Strengthening.** Investment in this area will allow CDC to provide scientific assistance across a range of topics related to the introduction of IPV to focus countries, other GAVI-eligible countries, and to non-eligible countries.

Continued funding will allow CDC to fully capitalize on the resources of the Emergency Operation Center to provide direct support and build capacity to continue intense supplementary immunization activities in the remaining polio-affected countries, continue leadership on data management to drive evidence-based decision making, and continue to implement strategies to increase effective management and accountability. These funds will also help maintain essential certification standard surveillance.

BENEFITS OF POLIO ERADICATION

Since 1988, over 10 million people who would otherwise have been paralyzed are walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 145 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other deadly infectious diseases and will do so long after polio is eradicated.

A study published in the November 2010 issue of the journal *Vaccine* estimates that the GPEI could provide net benefits of at least $40-50 billion. Polio eradication is a cost-effective public health investment with permanent benefits. On the other hand, as many as 200,000 children could be paralyzed annually in the next 10 years if the world fails to capitalize on the more than $10 billion already invested in eradication. Success will ensure that the significant investment made by the US, Rotary International, and many other countries and entities, is protected in perpetuity.

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

Introduction

Chairman Kingston, Ranking Member DeLauro, and Distinguished Members of the Subcommittee: on behalf of health centers across the nation, we wish to thank you for the opportunity to submit testimony for the committee to review as you craft the Fiscal Year (FY) 2015 Labor-Health and Human Services-Education and Related Agencies Appropriations bill. We also wish to thank you for your consideration of our FY2015 funding request of **$5.1 billion in total program funding** - $1.49 billion in level discretionary funding and for access to the $3.6 billion in available funding for the program under the Health Center fund for the Health Center Program through HRSA.

Health Centers- General Background

Health Centers are community-owned and operated non-profit entities providing primary medical, dental, and behavioral health care as well as pharmacy and a variety of enabling and support services. Today, there are over 1,200 health centers operating at more than 9,000 urban and rural communities nationwide. We are the "health care home" for more than 22 million patients in all 50 states and nearly every Congressional district.

By statute and mission, health centers are located in medically underserved areas or serve a medically underserved population. Health centers are directed by patient-majority boards, a model which helps to ensure they are responsive to the needs of each individual community they

serve. Health centers offer comprehensive care to all residents of the community who seek their care, regardless of ability to pay or insurance status and offer services on a sliding fee scale. Our unique model of care has enabled us to save the entire health system approximately $24 billion annually. Health Centers reduce preventable hospitalizations and Emergency Department use, as well as the need for more expensive specialty care. The services provided at health centers save $1,263 per patient per year compared to expenditures for non-health center users.

In addition to reducing costs, health centers also serve as small businesses and economic drivers in their communities. In 2012, health centers employed 153,000 individuals and in 2009 generated $20 billion in total economic benefits in poor urban and rural communities.

FY 2014 Funding Background

In FY 2014, health centers received a total of $3.7 billion in total federal funding. This includes $1.49 billion in discretionary funding provided by the Health Resources and Services Administration (HRSA) and $2.2 billion in mandatory funding for health centers through the Health Center Fund. We want to thank the members of this Subcommittee for their support of health centers within the Consolidated Appropriations Act of 2014 to ensure health center funding continues to reach communities in need.

Access to a Health Center Reduces Barriers to Primary Care

NACHC's recently released a report entitled: *Access is the Answer* finds 62 million Americans lack regular access to primary care and the vast majority of these medically disenfranchised Americans actually have insurance coverage. Many individuals still face barriers such as availability, affordability, and accessibility to primary and preventive care. Even among people who have an insurance card, access may be out of reach because of who they are and where they live. As health reform changes the health care landscape, we know that demand for

health centers will continue to climb among the uninsured, underinsured and underserved due to the lack of other health care providers willing to see our patients.

In communities with a Health Center, demand often exceeds supply and significant unmet need remains due to limited resources. True "access" means having a regular, reliable source of quality preventive and primary health care and simply having an insurance card does not guarantee ready access to primary care. With our unique model of care, Health Centers can help address these primary care demands in a cost effective manner. However, Health Centers cannot continue to deliver results without a sound financial base.

FY 2015 Funding Request and Health Center Funding Cliff

In FY2015, Health Centers are respectfully requesting level discretionary funding of $1.49 billion for the Health Center program. Together with the $3.6 billion in funding available in FY2015 through the mandatory Health Center Fund, health centers are requesting a total of $5.1 billion in total program funding. This funding for the Health Center program, **which requires no new appropriation from this Subcommittee**, should be fully utilized during FY2015 to increase access to primary care in medically underserved communities. With access to all available funding for the program in FY2015, Health Centers could build the capacity to serve up to 11 million new patients, both in new communities and through expanded services and capacity at existing health centers. In addition, existing Health Centers could ensure they are keeping up with current patient demand.

The President's proposed FY 2015 Health Resources and Services Administration (HRSA) budget provides $1 billion in discretionary funding for the Health Centers program. Together with the $3.6 billion in FY 2015 mandatory funding available for health centers, under the President's proposal, health centers would receive a net increase of $960 million in total

programmatic funding for FY 2015 equaling total funding of $4.6 billion. Within this proposal, the President will allocate $860 million for one-time quality improvement and capital development awards and $100 million to fund new health center sites.

We strongly oppose the President's proposed $500 million discretionary funding reduction for health centers as it further reduces the discretionary allocation for the program beyond the levels in place prior to the inception of the Health Center Fund. Health centers simply cannot survive further decreases to their base discretionary funding which undermines the long-term sustainability of the program, and may well threaten access for existing patients. The President's proposal for FY2015 falls well short of the Health Center program's effort to meet the increasing demands accessible to care and what is currently in the law, especially since enrollments into coverage whether through Medicaid or exchanges have been much lower than anticipated.

We do appreciate the President's acknowledgement and recognition of the looming funding crisis for health centers upon the expiration of the Health Center Fund after FY2015. Under current law the Health Center Fund will end after FY2015, resulting in as much as a **70 percent** reduction in health center grant funding in FY2016. Averting the health center cliff is critical to ensuring that health centers remain financially viable and able to serve the diverse needs of their communities. However, the President only proposes a temporary (3 year) solution reducing program funding down to FY2014 levels after a one-time increase in FY2015. Given the number of communities and individuals in need of access to health care, longer-term solutions must encompass both stability and expansion of access to care.

If primary care is not accessible in the communities in which these people live, they will seek it out in emergency departments and hospitals, often waiting until they are sicker. This will

mean poorer health for these patients and much higher costs to the system. We look forward to working with the Subcommittee to continue toward our shared goal of expanding and ensuring access to quality and affordable health care to all Americans.

Conclusion

We understand this Subcommittee must make difficult budgetary decisions as you work within the funding limits set for the subcommittee's bill. As the FY2015 appropriations process moves forward, we urge you to keep in mind that without their local health center, medically underserved communities and patients would often be without any access to primary care. Barriers such as availability and affordability of care as well as geography and language difficulties often cause individuals to put off or delay needed preventive care services and the demand for primary care providers has outpaced supply in many places across the nation.

Health Centers are more than a safety net. They have a demonstrated track record of improving the health and well-being of their patients using a locally-tailored health care home model designed to coordinate care and manage chronic disease at the same time reducing unnecessary, avoidable and wasteful use of health resources. Without access to primary care, many people, including the chronically ill, delay seeking health care until they are seriously ill and require inpatient hospitalization or care at an emergency room at a much higher cost.

Health centers have continually proven to be a worthwhile investment by delivering high quality, affordable health care while generating savings to the entire health system. We work continuously to improve patient health, while saving taxpayer dollars. We are extremely grateful for your past support and ask for the Subcommittee's continued support for the Health Center program. We look forward to working with you and thank you for your consideration.

Submitted by: Joseph C. Isaacs, Chief Executive Officer, NBCA, 110 North Washington Street, Suite 328, Rockville, MD 20850, 301-825-9214, jisaacs@stoptheclot.org

Statement for the Record Presented by the National Blood Clot Alliance to the House Committee on Appropriations' Subcommittee on Labor, Health and Human Services, Education and Related Agencies
March 28, 2014

The National Blood Clot Alliance (NBCA) is pleased to submit this statement in support of increased appropriations for fiscal year 2015 for the Centers for Disease Control and Prevention's (CDC) Division of Blood Disorders, a component of CDC's National Center on Birth Defects and Developmental Disabilities. NBCA's statement addresses the programs specific to blood clots, known scientifically as Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE), a major public health problem facing this nation. Combined, these disorders are known as venous thromboembolism (VTE). Preventing death and disability from VTE is an important public health priority, and the Division is responsible for all CDC activities related to blood clots and other bleeding disorders. NBCA asks the Subcommittee to restore funding for the Division to its fiscal year 2010 level, $19.9 million. The FY 2014 funding has dropped precipitously to $13 million. Of this, support for blood clot prevention has been cut in half, to a mere $560,000, hardly enough to make a dent in a major public health problem that annually kills more Americans than AIDS, breast cancer and motor vehicle accidents combined. NBCA further requests that the Subcommittee establish a budget line item specific to blood clots and clotting disorders and that $4 million be appropriated for this line each year for the next five years.

Funding this program at the requested level will be a major step in advancing the Surgeon General's 2008 *"Call to Action to Prevent Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)"* and the nation's *"Healthy People 2020 Objectives."* The urgency of this request is underscored by the fact that the great majority of blood clots could be prevented. We have the tools to do that, but the resources to deploy them are woefully inadequate. Blood clots are the leading cause of unnecessary hospital readmissions in the U.S., costing our nation an estimated $10 billion dollars in avoidable health care expenses annually. According to the American Public Health Association, DVT deaths are the most common preventable cause of hospital death. Researchers at Johns Hopkins University School of Medicine recently reported that as many as 70 percent of health care associated VTE could be eliminated with the application of improved prevention protocols. Other targeted population-based prevention tools can be applied to avert disability and death from blood clots due to aging, lengthy travel, immobility, obesity and other risk factors.

The National Blood Clot Alliance

Founded in 2003, NBCA is a patient led non-profit, voluntary health organization dedicated to advancing the prevention, early diagnosis and successful treatment of life-threatening blood clots such as deep vein thrombosis, pulmonary embolism and clot-provoked stroke. We work on behalf of people who have or could be susceptible to blood clots, including, but not limited to, people with clotting disorders, atrial fibrillation, cancer, traumatic injury, and risks related to surgery, lengthy immobility, child birth and birth control. NBCA accomplishes its mission through programs that build public awareness, educate patients and

healthcare professionals and promote supportive public and private sector policy. Our content is reviewed by an internationally recognized Medical and Scientific Advisory Board. We invite the Members of the Subcommittee to visit our website at www.stoptheclot.org to learn more about blood clots and the programs of NBCA.

Who Has Blood Clots and What Are They?

No American is immune from blood clots, regardless of age, gender, race, ethnicity or health status. Normal blood clots play an important role in protecting our health because they stop bleeding from a cut or wound. However, blood clots can also form abnormally, causing a heart attack, stroke, or other serious medical problems. Experts estimate that two million Americans suffer such venous and arterial blood clots every year. More than 200,000 Americans die from them annually. An often silent killer, death can be sudden with no forewarning. But in most instances, the damage can be averted or contained. Age, smoking, obesity can all contribute to clotting risk, but so can birth control or pregnancy or cancer. Even prominent athletes in peak physical condition have suffered career- ending, life -threatening clots. It can happen to any of us. In fact, the memories of former U.S. Reps. Walter Capps (D-CA) and Jennifer Dunn (R-WA), who died due to blood clots while serving in Congress, motivated the creation of National Blood Clot Awareness Month in March of 2009.

Physicians estimate that as little as 20 percent of blood clots are actually recognized for what they are. Misdiagnosis and delayed diagnosis are all too common and all too often fatal. The general public is even farther behind, with surveys showing that nearly three quarters of the population has little or no knowledge about blood clots, their risks, their signs and symptoms and their prevention. The government must play a greater role in educating the

general public, people who are at special risk and health professionals. This is the "low hanging fruit" of public health prevention that has yet to be adequately picked and the return on invest can be tens of thousands of lives saved and billions of dollars in unnecessary health care expenses avoided!

The Federal Role Has a Vital Role in Meeting this Acknowledged Public Health Priority

Many federal agencies play important roles in the effort to reduce death and disability from blood clots and clotting disorders. The National Institutes of Health and the National Science Foundation support the work of basic scientists in their efforts to understand the causes and effects of blood clots and identify improved treatments. The VA also supports research in this field and strives to prevent blood clots in the special population of Americans it serves. The Agency for Healthcare Research and Quality in 2001 was among the first to recognize that blood clot prevention in hospitals was our best opportunity for patient safety improvement. The *Partnership for Patients* makes made blood clot prevention a key component of improved hospital care. *CMS* includes surgery-related blood clot prevention as a key measure of hospital quality. DOD has examined how blood clots can be prevented in the military, affecting soldiers who must often live in cramped conditions, suffer dehydration and experience bone fractures and more severe injuries that require surgery.

Each of these agencies plays a special role in the effort to reduce clotting death and injury. However, the CDC, the nation's leading prevention agency, is the one best suited to guide and coordinate federal efforts targeted at populations more broadly. No other agency possesses its unique capabilities in public health outreach, education and promotion. Regrettably the agency best suited for leadership is the one with the fewest resources. NBCA

believes it is imperative that Congress act now to provide adequate, sustained funding for this specific activity at CDC—the reduction of death and disability due to blood clots.

The funding request presented at the beginning of this statement will provide CDC with the resources it needs to begin seriously to meet this public health challenge. FY 2014 funding for blood clot programs is only $560,000, half of what was available in the last fiscal year. The Administration's proposed FY 2015 budget would make no change to this level. The current funding situation for the Blood Disorders Division has already forced CDC to cut or curtail the few programs it has been able to support. These include two pilot programs to improve community-based VTE surveillance and evaluation; one focused on health care provider education; one targeted at women's health (e.g., blood clots are the leading cause of maternal mortality); and a collaboration with the VA and academia to develop new VTE surveillance tools. Staffing of the Division has also been cut nearly in half, decreasing by 18 FTEs, including essential personnel with specialized laboratory, IT and analytic skills. At a time when this public health problem is growing, we have allowed even the small investment in CDC to address it become further negligible. This is neither thoughtful public policy nor wise economically.

NBCA believes that our citizens deserve better and that federal support for this acknowledged public health priority should be equal to the task. Tragically, it is not at present. NBCA urges the Subcommittee to take the lead in making the changes needed to provide CDC with the funds it needs to combat this major public health issue—blood clots, clotting disorders and the ensuing disability that consumes far too many lives and dollars in the U.S. unnecessarily.

Written Testimony of Denise Bowers, RDH, PHD
President, American Dental Hygienists' Association
Submitted to the
Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies
United States House of Representatives
The Honorable Hal Rogers, Appropriations Committee Chair
The Honorable Jack Kingston, Subcommittee Chair
FY 2015 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 FY 2015 appropriations. 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 urges that the block on funding for Section 340G-1 of the Public Health Service Act – a much-needed dental workforce demonstration program – be lifted and that $1.25 million be appropriated.** Lifting the block on this dental workforce grants program, officially titled the Alternative Dental Health Care Providers Demonstration Program, would send an important signal to states and to HRSA that innovation in dental workforce is a meritorious undertaking. Importantly, the authorizing language requires that the grants be conducted in compliance with state law and that they must increase access to dental health care in rural and other underserved communities. Further, the Institute of Medicine is required to provide a qualitative and quantitative evaluation of the grants.

Congress recognized the need to improve the oral health care delivery system when it authorized the Alternative Dental Health Care Provider Demonstration Grants, Section 340G-1 of the Public Health

Service Act. The Alternative Dental Health Care Providers Demonstration Grants program is a federal grant program that recognizes the need for innovations to be made in oral health care delivery to bring quality care to the underserved by pilot testing new models. The authorizing statute makes clear that pilots must "increase access to dental care services in rural and underserved communities" and comply with state licensing requirements.

New dental providers are already authorized in Minnesota and are under consideration in a number of states, including Connecticut, Kansas, Maine, Massachusetts, New Hampshire, New Mexico, Vermont, and Washington State. Both the W.K. Kellogg Foundation and the PEW Charitable Trust Dental Campaign are investing in state efforts to increase oral health care access by adding new types of dental providers to the dental team. Further, the U.S. Federal Trade Commission supported dental workforce expansion in December 2013, noting that "expanding the supply of dental therapists... is likely to increase the output of basic dental services, enhance competition, reduce costs and expand access to dental care." The National Governors Association's January 2014 issue brief on "The Role of Dental Hygienists in Providing Access to Oral Health Care" found that "innovative state programs are showing that increased use of dental hygienists can promote access to oral health care, particularly for underserved populations, including children" and that "such access can reduce the incidence of serious tooth decay and other dental disease in vulnerable populations.

The FY2014 HHS funding bill included language designed to block funding for this important demonstration program. We seek your leadership in removing this unjustified prohibition on funding for the Alternative Dental Health Care Providers Demonstration Grants. Further, because the authorizing language required HRSA to begin the dental workforce grant program under Section 340G-1 within two years of its 2010 enactment (i.e., by 2012) and to conclude it within seven years of enactment (2017), language directing HRSA to move forward with Section 340G-1 grants despite this timeline is needed. ADHA, along with more than 60 other oral health care organizations, advocated for funding of this

important program. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated. ADHA recommends funding at a level of $1.25 million for FY 2015 to support these vital dental workforce demonstration projects.

Additionally, ADHA joins the American Dental Association, the American Dental Education Association and others in the oral health community in recommending $32 million for Title VII Program Grants to expand and educate the dental workforce; $19 million for oral health programming at CDC, and funding of $425 million for National Institute of Dental and Craniofacial Research.

ADHA urges 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 $32 million in FY 2015

A number of existing grant programs offered under Title VII support health professions education programs, students, and faculty. ADHA is pleased dental hygienists are recognized as primary care providers of oral health services and are included as eligible to apply for several grants offered under the "General, Pediatric, and Public Health Dentistry" grants. 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.

Oral Health Programming within the Centers for Disease Control –
Fund at a level of $19 million in FY 2015

ADHA joins with others in the dental community in urging $19 million for oral health programming within the Centers for Disease Control. 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 will serve to

facilitate improved oral health leadership at the state level; support the collection and synthesis of data regarding oral health coverage and access, promote the integrated delivery of oral health and other medical services; enable states to be innovative and promote a data-driven approach to oral health programming.

National Institute of Dental and Craniofacial Research –
Fund at a level of $425 million in FY 2015

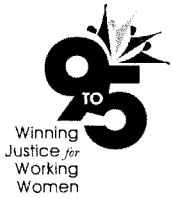
The National Institute of Dental and Craniofacial Research (NIDCR) cultivates oral health research that has led to a greater understanding of oral diseases and their treatments and the link between oral health and overall health. Research breeds innovation and efficiency, both of which are vital to improving 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 $425 million in FY 2015.

ADHA is the largest national organization representing the professional interests of more than 150,000 licensed dental hygienists across the country. In order to become licensed as a dental hygienist, an individual must graduate from one of the nation's 335 accredited dental hygiene education programs and successfully complete a national written and a state or regional clinical examination. 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 the past decade, the link between oral health and total health has become more apparent and the significant disparities in access to oral health care services have been well documented. At this time, when 130 million Americans struggle to obtain the oral health care required to remain healthy, Congress has a great opportunity to support oral health prevention, infrastructure and workforce efforts that will make care more accessible and cost-effective.

Conclusion

ADHA appreciates the difficult task Appropriators face in prioritizing and funding the many meritorious programs and grants offered by the federal government. **ADHA urges the Committee to lift the block on**

funding for Section 340G-1 of the PHSA, dental workforce demonstration grants. Lifting the block on funding for these dental workforce grants would be an important signal to states and to health care stakeholders that exploring new ways of bringing oral health services to the underserved is a meritorious expenditure of resources. In addition to the items listed, ADHA also supports full funding for community health centers, and urges HRSA be directed to further bolster the delivery of oral health services at community health centers, including the use of new types of dental providers. 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.



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Testimony in Support of the State Paid Leave Fund
Submitted to the U.S. House of Representatives Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Linda Meric, Executive Director, 9to5
March 28, 2014

On behalf of the members of 9to5 across the country, I respectfully urge the Committee on Appropriations to include the State Paid Leave Fund, administered through the Department of Labor, and the $105 million funding for it proposed in the President's budget, in the Fiscal Year 2015 Labor, Health and Human Services and Education bill. The State Paid Leave Fund would create a competitive federal grant fund designed to spur innovation among states interested in creating family and medical leave insurance (FMLI) programs, as well as those with established FMLI programs, and has the potential to help millions of American families maintain economic security.

9to5 is a 41-year-old national membership organization of women in low-wage jobs working to improve workplace and public policy on issues related to equal opportunity, quality jobs, workplace flexibility and economic security. 9to5 helped lead the effort to pass the federal Family and Medical Leave Act (FMLA) in 1993, and our members have worked in the states to make FMLA more accessible and affordable.

9to5 members and their families are directly affected by the lack of paid leave. As Shelby Ramirez, a 9to5 member from Denver, Colorado, states, "When my younger daughter needed surgery at the same time that my elderly father needed immediate medical attention, I was able to use the Family and Medical Leave Act to take time off from work to care for them. But I am employed in a low-paid job, and having to take unpaid leave was an enormous financial burden for me. I had to choose between paying rent or caring for my family, between medications and meals. After this crisis, it took me four months to get caught up with my bills. Although FMLA ensured that I was able to keep my job, having **paid** family and medical leave is necessary now and for the future of our families."

At some point in their working lives, almost all Americans will, like Shelby, need to take time off to care for a new baby or adopted child, an ailing child or parent, or their own health. The Family and Medical Leave Act – the only federal law designed to help

working people meet the dual demands of job and family – leaves out 40 percent of the workforce and guarantees only unpaid leave, which millions cannot afford to take. And only 12 percent of U.S. workers currently have access to paid family leave through their employers. That means millions of workers who develop serious health conditions, have seriously ill family members or become parents are forced to choose between what is best for them and their families and income they need to cover basic expenses.

Family and medical leave insurance programs at the state level allow workers to pay a small portion of their wages each week for the guarantee that when they need it, they can receive a percentage of their wages while they have to take extended family or medical leave from work. These programs help working families stay afloat when they need time off to care for an ill family member, a new baby or their own health.

Three states – California, New Jersey and Rhode Island – have created family and medical leave insurance programs. Research has shown that paid leave programs contribute to increased family financial stability and improved child well-being, better workforce outcomes for new parents, reductions in government public assistance expenditures, and cost-savings for businesses.

That's why there is broad support among the business community for paid family and medical leave programs. Businesses understand it's good for their bottom line. California employers report that the program has had a neutral or positive effect on employee productivity, profitability, and turnover, and most employers coordinate their own benefits with the state's paid family leave program. A 2011 study of California's family and medical leave insurance program estimated that it would save employers $89 million a year. A recent Rutgers study shows that New Jersey's family and medical leave insurance program has saved businesses money by improving employee retention, decreasing turnover costs, and improving productivity.

A federal grant program would help states with one-time start-up costs to develop and implement successful family and medical leave insurance programs that are so needed across the country. Once these insurance programs are up and running they become self-sustaining. Without this federal support, the initial capital needed to design and launch these programs would continue to act as a roadblock, despite broad public support.

The State Paid Leave Fund would benefit both states considering a family leave and medical insurance program and states with an existing program. States with established FMLI programs could apply for grants to increase awareness about and utilization of the program by conducting outreach to ensure eligible workers who have been paying into

the program are accessing it when they need it. For many states considering programs, access to competitive federal grants that help defray the one-time costs of designing and launching these insurance programs would provide a compelling incentive to states to innovate.

For example, 9to5 is leading broad and diverse coalitions in Colorado and Wisconsin to enact family and medical leave insurance. As Coloradans actively advance an FMLI program, the potential start-up capital from the State Paid Leave Fund could help defray the one-time design and launch costs, and would break down the critical barrier of initial cost before the program becomes self-sustaining. In Wisconsin, where 9to5 and community partners are actively laying the groundwork to advance family and medical leave insurance legislation, the State Paid Leave Fund could help fund necessary cost-benefit analysis and program development that may otherwise be hindered by state budget constraints.

A modest investment at the federal level in the State Paid Leave Fund would translate to significant impact for millions of families' economic security. In sum, there is tremendous support across the country for creating a new State Paid Leave Fund. Nearly a dozen states could immediately benefit from federal funds made available through a competitive grant program. On behalf of 9to5 members across the country, I urge you to pass a budget bill with $105 million allocated for the State Paid Leave Fund to help states with programs that benefit working families, businesses, and the local economy.

Respectfully submitted by
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March 27, 2014

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

FROM: Joan Kelley, Legal Guardian; Vice-President, KNI Parent Guardian Group

REGARDING: 2015 Budget, Department of Health and Human Services, Testimony for the Record

Thank you for the opportunity to provide testimony for the record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. I strongly object to the use of United States Department of Health and Human Services (HHS) appropriation funds currently being funneled to entities using deceptive tactics that have resulted in the forced eviction of some of our most vulnerable from safe environments. I hereby request that Congress take action to prohibit federal funds from being allocated to programs which are promoting and establishing dangerous policies that force persons with the most extreme forms of Intellectual and Developmental Disabilities into harm's way by closing Intermediate Care Facilities.

As the Guardian of a profoundly disabled young man, I have a vested interest in this matter. Having navigated and utilized a broad spectrum of community services for over 15 years for my grandson, my final recourse after exhausting every community option was to place my loved one at the Kansas Neurological Institute, because no one in the community was able to handle him. Since his placement at KNI our loved one has been well cared for, and restored to a place of stability unparalleled in the community. We have tried without success to reintegrate him into

the community as more than a a few community providers have refused to serve him.

Facilities like KNI are the safety net for those whom the community is not suitable or has failed to keep safe, yet these havens are under attack nation-wide. A number of HHS funded programs are displacing our most vulnerable without regard to clarifications in the Supreme Court Olmstead ruling, which highlights individual choice, need and safety. Groups including the ARC, National Council on Disabilities, State DD Councils, Universities for Excellence, and State Protection and Advocacy have ignored mounting evidence of tragic community outcomes. These federally funded entities appear to collaborate and push the extreme agenda of forced closure of all State "institutions". This radical agenda fails to recognize community capacity issues and an increasing number of documented tragedies in our communities. One example of how government dollars, through HHS appropriations use under-handed methods, promoting policies to close institutions serving our most vulnerable include: The National Council on Disability (NCD) - an independent federal agency funded through HHS appropriations. In October 2012 the NCD released a "De-institutionalization tool-kit" to accomplish the closure of Medicaid-certified specialized homes. Families and guardians including myself, have expressed opposition to NCD's misuse of their authority and federal funding, yet little oversight or accountability is executed over the Council. The NCD has been called upon to reject their stance on forced deinstitutionalization, yet this agency has thus far ignored pleas to reconsider. They have failed to acknowledge the most important stakeholders: parents and guardians of those with the most profound needs.

Despite extensive documentation of widespread abuse in community settings,

the NCD continues to press their idealistic position. They continue to ignore problems like understaffed homes, underpaid, poorly trained direct care staff, and high community staff turnover. They also continue to ignore correlating evidence in the form of documented tragic outcomes for our most vulnerable citizens. In many cases, these are the very people they claim to represent and protect. The very idea that ALL individuals with intellectual /developmental disabilities can and should be served in their particular version of "community" is in direct conflict with clarifications in the Supreme Court Olmstead ruling.

Regarding choice and safety for those with little or no self-preservations skills.... (we are not talking about higher-functioning DD individuals showcased on Public Television or who serve on DD Councils) we ARE talking about those who cannot speak, those who cannot push a button to communicate, and those who cannot defend themselves. These are the people who need our help most because they will most likely NEVER be considered for employment of ANY kind.

Most recently the NCD submitted recommendations to the Center for Medicaid Services (CMS), specifically targeting the Kansas implementation of Kan-care In their testimony. They declared "institutions" as the "poorest quality at the highest cost"

(NCD Follow Up Letter to CMS about Amendment to Kancare Medicaid Section 1115, January 14, 2014, www.ncd.gov) These recommendations were given to CMS in spite of extensive documentation of community abuse submitted to them! During the NCD's December quarterly meeting here in Kansas, I personally submitted professionally bound, extensive documentation of de-institutionalized individuals severely abused in Kansas communities, with no response from NCD.

Additionally, the NCD ignored the 2011 KNI Legislative Post-Audit's confirmed estimates of higher community costs for targeted transition individuals, higher than current CMS per diem funding rates for those served in state facilities. * ***(2011 KNI Legislative Post Audit, appendices, Pages 61-64)***

As an independent federal agency charged with advising the President and Congress, the NCD should not be taking any position which tramples on the rights of a portion of the disability community. They certainly should not trample on the weakest members of our society who are unable to hold a pencil and write this defense for themselves.

While it is true that some individuals with high needs have been served in the community, consider also that your colleague Senator Chris Murphy called for an in depth investigation of widespread community abuse of our most vulnerable.

*(**Courant.com - Senator Urges Federal Probe Into Abuse, Neglect Of Developmentally Disabled** - MATTHEW KAUFFMAN mkauffman@courant.com The Hartford Courant - 6:47 PM EST, March 4, 2013.)* Additional documentation of abuse and even deaths provided by the following source: - **New York Times - November 5, 2011: In State Care, 1,200 Deaths and Few Answers**

This has been going on for more than a decade. Newspaper accounts of poor quality in community Long Term Service systems abound, including: *Hartford Courant*. (December 2, 2001). "The Toll: Suffocation, Drowning, Choking, Burns." *Oregon Statesman Journal*. (March 12, 2000). "A Rash of Deaths, Inquirers Find Neglect a Factor." Boo, K. (March 14, 1999). "Forest Haven is Gone, but the Agony Remains." *The Washington Post*, p. A1. *The Washington Post*. (March 15, 1999).

"Residents Languish; Profiteers Flourish." The ideological agenda of forced closure of facilities caring for our weakest is utterly cruel.

The real civil rights issue at hand is the disregard for those who have been forced from safe environments by pervasive deinstitutionalization without considering true capacity-building to serve those with the greatest need. The entities mentioned above have neglected to ensure extensive supports that include trained, adequately paid, dedicated staff and solid accountability parameters in their over-reaching push of "Community for all." I have not even touched on the lack of professional oversight necessary to attend to quality of care issues surrounding our most helpless living in scattered homes across each state. However, my request is that you consider the human impact as so far presented, as these, the "least of these" brothers and sisters did not choose to be born this way, and deserve your very best.

In conclusion I call upon Congress to introduce and support language prohibiting the use of HHS appropriations for closure activities under the cloak of "inclusion". Putting defenseless people into harms way through forced eviction without prioritizing capacity building is a dereliction of duty. Suggested language has been respectfully submitted to several Committee members, including the Kansas Congressman Kevin Yoder for review. Thank you for your consideration and willingness to find true solutions to this most troubling trend and to consider ways of stopping the tragedies resulting from it.

Respectfully,

Joan Kelley 36050 W 154 St Gardner, Kansas

National League *for* **Nursing**

Testimony Regarding Fiscal Year 2015 Appropriations for Title VIII Nursing Workforce Development Programs and Nurse-Managed Health Clinics Programs
March 28, 2014

Submitted by: Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing

To: Subcommittee on Labor, Health & Human Services, and Education, Committee on Appropriations, U.S. House of Representatives

The National League for Nursing (NLN) urges the subcommittee to fund the following in FY 2015:

- **$251 million for the Title VIII Nursing Workforce Development Programs administered by the Health Resources and Services Administration (HRSA); and**
- **$20 million for the Nurse-Managed Health Clinics authorized under Title III of the *Public Health Service Act*.**

The NLN is the premiere organization dedicated to promoting excellence in nursing education to build a strong and diverse nursing workforce that advances the nation's health. With leaders in nursing education and nurse faculty across all types of nursing programs – doctorate, master's, baccalaureate, associate degree, diploma, and licensed practical – the NLN has more than 1,200 nursing school and health care agency members, 40,000 individual members, and 26 constituent leagues.

NURSING EDUCATION IS A JOBS PROGRAM

The March 7, 2014, U.S. Bureau of Labor Statistics (BLS) ***Employment Situation Summary – February 2014*** points to the nursing workforce's strength in creating job growth. While the nation's overall unemployment rate was little changed at 6.7 percent for February 2014, the employment in health care with the addition of 10,000 jobs amounted to an unemployment rate of only 4.0 percent in the industry. BLS notes that the health care sector is a critically important industrial complex for our nation. It is at the center of the economic recovery with the number of jobs climbing steadily. Growing even when the recession began, health care jobs are up nationwide. Almost five million

workers are in hospital settings, which often are the largest employer in any congressional district. Health care has been a stimulus program generating employment and income, and nursing is the predominant occupation in the health care industry, with more than 4.031 million active, licensed registered nurses (RN) in the United States.

According to the BLS, the RN workforce will grow by 19.4 percent from 2012 to 2022, outpacing the 11 percent average for most occupations. BLS projects that this growth will result in 1,052,600 job openings, representing one of the largest numeric job increases for all occupations. BLS calculates the openings from an increase of 526,800 RN jobs due to technological advancements fueling growth in treatments, preventive care being emphasized more, expanding demand from new health reform enrollments, and accelerating demand from the two million Baby Boomers aging into Medicare every year. A particularly disconcerting element of the probable RN job openings is a loss of nursing expertise owing to the replacement need of some 525,700 jobs vacated by RNs expected to leave the profession and/or retire from the labor force by 2022.

THE NURSE PIPELINE AND EDUCATION CAPACITY

Although the recession resulted in some regional stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their districts and states. The NLN's findings from its ***Annual Survey of Schools of Nursing – Academic Year 2011-2012*** cast a wide net on all types of nursing programs to determine rates of application, enrollment, and graduation. Key findings from the NLN research include:

- **Demand for spots in nursing education programs historically outstripped supply.** In 2011, 43 and 48 percent of master's and doctoral nursing programs, respectively, rejected qualified applicants. More dramatically, well over 80 percent of programs offering practical nursing (PN) degrees and associate's degrees (ADN) were forced to turn away qualified candidates, as did almost two-thirds of baccalaureate in science of nursing (BSN) programs.

- **Age of associate degree students rises.** A substantial increase in the percentage of ADN students who were over 30 years old occurred, rising in 2012 to 50 percent of the student nursing enrollments. Because ADN students comprise two-thirds of all pre-licensure RN enrollees, this uptick in enrollments among older students could reignite concerns over an aging nursing workforce and the potential for future labor shortages.
- **Expansion of nursing education programs impeded by shortage of faculty.** Deans and directors of schools providing programs that did not accept all eligible applicants were asked to identify the primary obstacle to expanding their program's capacity. Since 2010, the percentage of those directing ADN and PN programs who cited a shortage of clinical sites as the primary impediment to expansion has steadily increased. For PN programs in particular, the percentage jumped to 51 percent in 2012. By contrast, graduate programs consistently cite a lack of faculty as the primary obstacle to expansion. A strong correlation exists between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new nurse faculty and new RNs. Increasing the productivity of education programs is a high priority in most states, but faculty recruitment is a glaring problem. Without faculty to educate our future nurses, the shortage cannot be resolved.

Title VIII Federal Funding Reality

The Title VIII Nursing Workforce Development Programs are a comprehensive system of evidence-based, 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. A few examples of HRSA's Title VIII data below provide perspective on current federal investments.

Nurse Faculty Loan Program (NFLP) – BLS projects a need of 35 percent more faculty members to meet the expected increase in demand. NFLP supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate education to become qualified nurse faculty. Ongoing NFLP support for faculty production is critical to building the pipeline that assures the full capacity of the nation's future nursing workforce. Targeting a portion of those funds for minority faculty preparation is fundamental to achieving that goal. In FY 2012, NFLP grantees exceeded the program's performance target by 49.6 percent in providing loans to 2,259 students pursuing faculty preparation. About one out of every four students receiving the NFLP loans were considered underrepresented minorities.

Comprehensive Geriatric Education Program (CGEP) – CGEP provides support to educate individuals in providing geriatric care for the elderly. Goals are accomplished through curriculum development and dissemination, continuing education, and traineeships for individuals preparing for advanced nursing education degrees. In FY 2012, CGEP grantees awarded traineeships to 74 students – the majority of whom (81 percent) were pursuing a Master's Degree in Nursing.

Nurse Education, Practice, Quality, and Retention Grants (NEPQR) – NEPQR addresses the critical nursing shortage via projects to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. Grants to support recruiting and retaining nursing assistants and personal and home care aides in occupational shortage and/or high demand areas trained 4,624 students during FY 2012. NEPQR also supported expanding the size of BSN programs and supported nurse-managed health clinics.

NURSE-MANAGED HEALTH CLINICS (NMHC)

NMHCs are a nurse-practice arrangement, managed by advanced practice registered nurses, that provides primary care or wellness services. NMHCs are associated with a school, college, university, or department of nursing, federally qualified health center, or independent nonprofit health or social

services agency. NMHCs deliver comprehensive primary health care services, disease prevention, and health promotion for vulnerable and specialized populations (e.g., veterans and/or families of active military). The complexity of care for these patients presents significant financial barriers, heavily affecting the sustainability of these clinics. While providing access points in areas where primary care providers are in short supply, expansion of NMHCs also increases the number of structured clinical teaching sites available to train nurses and other primary care providers. In FY 2012, more than 1,600 health professions students were trained in NMHCs, where the majority of NMHCs and associated training sites were primarily located in medically underserved communities (97 percent) and served as a primary care setting for their local community (65 percent). Appropriating $20 million in FY 2015 to NMHCs would increase access to primary care for thousands of underserved people.

The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. The positive trend, however, does not override concern for filling the projected BLS job estimates. The NLN cautions that absent consistent support, recent expenditures to Title VIII will not meet the expectation of paying down on investments in a nurse workforce that generates quality health outcomes. Nor will episodic increases in the funding of Title VIII fully attain the goal of building and maintaining a workforce set to meet the challenges of our fast-changing health system, prepared to take care of you, your family, and all those who will need our care.

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Written Testimony of Safe States Alliance Executive Director, Amber Williams, to the House Committee on Appropriations

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

Safe States Alliance, the national membership association dedicated to strengthening the practice of injury and violence prevention, appreciates the opportunity to provide testimony in support of the Centers for Disease Control and Prevention (CDC). Safe States Alliance requests that the CDC's National Center for Injury Prevention and Control (Injury Center) receive $205.5M in FY15 – an additional $29.7M for the Core Violence and Injury Prevention Program (VIPP), including resources to meaningfully address the epidemic of prescription drug misuse, abuse and overdose; and an additional $13.7M for the National Violent Death Reporting System (NVDRS). Safe States Alliances also supports continued funding of the CDC's Preventive Health and Health Services (PHHS) Block Grant at $180M.

BACKGROUND

In 1985, the Institute of Medicine (IOM) first called attention to the lack of recognition and funding for injury and violence prevention (IVP) as a public health issue in the United States.[1] Although some progress has been made in subsequent years, injuries and violence continue to have a significant impact on the health of Americans and the healthcare system, as more people ages 1–44 die from injuries than from any other cause, including cancer, HIV, or the flu.[2]

Injuries and violence are serious public health problems. Areas include:	
Assault & Homicide	Motor Vehicle Safety
Bullying	Pedestrian & Bicycle Safety
Child Maltreatment	Poisoning & Prescription Drug Overdose
Child Passenger Safety	Sexual Assault & Rape
Disaster Response	Suicide
Domestic & Intimate Partner Violence	Traumatic Brain Injury
Drowning	Youth Violence
Elder Abuse	
Falls	
Fire & Burns	

In fact, more than 29 million people are treated in emergency departments each year, two million are hospitalized, and approximately 180,000 people die—one person every three

minutes. Every 45 minutes, one of those preventable deaths is a child.[2] In a single year, injuries and violence will ultimately cost $406 billion in medical costs and lost productivity.[3] Yet to date, there is no national program to support state public health IVP programs.

At the federal level, the CDC Injury Center serves as the focal point for the public health approach to IVP. The CDC Injury Center only receives approximately two percent of the CDC/ Agency for Toxic Substances and Disease Registry budget to address the significant burden of injuries and violence nationwide. In FY 2013, the total Injury Center budget was only $138.9 million.

CORE VIOLENCE AND INJURY PREVENTION PROGRAM (VIPP) AND NEW PRESCRIPTION DRUG OVERDOSE PREVENTION EXPANDED COMPONENT

Given its limited budget, the CDC Injury Center currently provides small capacity building grants of approximately $250,000 to only 20 state health departments (SHDs) through the Core Violence and Injury Prevention Program (VIPP). The Core VIPP is comprised of multiple components including: Basic Prevention (20 states); Regional Network Leaders (five states); Surveillance Quality Improvement (four states); Older Adult Falls Prevention (three states); and Motor Vehicle/Child Injury Prevention (four states). The President's 2015 Budget Request includes an increase of approximately $15.6M to expand the number of funded Core VIPP programs ($5.6M) and to allow for the development of a new expanded component for states to address the epidemic of prescription drug misuse, abuse and overdose ($10M).

Opioid pain relievers are now involved in more overdose deaths than cocaine and heroin combined. The abuse of prescription opioid pain relievers costs up to $72 billion annually. The CDC Injury Center provides leadership in enhancing drug overdose surveillance, identifying and evaluating effective program and policy interventions for preventing overdoses, improving

clinical practice to reduce prescription drug diversion and abuse, and equipping and empowering states with the information and resources they need to reverse the epidemic. Core VIPP states would be funded to advance promising surveillance and prevention strategies and would complement other federal agencies, such as SAMHSA's work on screening, treatment and community prevention activities. State health departments are well positioned to coordinate the necessary multi-sector responses to reverse the epidemic through the regulation of health care professionals, prescription drug monitoring programs, and other major levers for preventing prescription drug abuse.

Ohio's Core Violence and Injury Prevention Program (VIPP) provides statewide leadership and funding for community-based efforts to address prescription drug abuse and overdose through the PHHS Block Grant from CDC. The OH VIPP coordinates the development and implementation of statewide prevention strategies, conducts surveillance, supports the Governor's Cabinet Opiate Action Team Prescriber Education Work Group including the development of opioid prescribing guidelines, and provides support and technical assistance to expand naloxone distribution programs. Examples of locally PHHS Block Grant funded strategies include: expanding access to naloxone distribution programs; facilitating health care system changes such as implementation of opioid prescribing guidelines and other pain management strategies; obtaining commitment of prescribers to use the Ohio prescription drug monitoring program; and expanding access to sustainable drug disposal options.

With overall program funding of $29.7M, the CDC Injury Center could support injury and violence prevention programs in ALL states and territories, much as it does for other key public health issues including chronic and infectious diseases, as well as make significant strides in reversing the prescription drug overdose epidemic.

NATIONAL VIOLENT DEATH REPORTING SYSTEM (NVDRS)

NVDRS is a state-based surveillance system that uses information from a variety of states and local agencies and sources – medical examiners, coroners, police, crime labs and death certificates – to form a more complete picture of the circumstances that surround violent deaths. State and local violence prevention practitioners use these data to guide their prevention programs, policies and practices including: identifying common circumstances associated with violent deaths of a specific type (e.g. gang violence) or a specific area (e.g. a cluster of suicides); assisting groups in selecting and targeting violence prevention efforts; supporting evaluations of violence prevention activities; and improving the public's access to in-depth information on violent deaths. CDC Injury Center currently funds 18 states to implement NVDRS and received an approximately $7.9M increase in FY 2014 to expand number of participating states.

The Oregon Older Adult Suicide Prevention Advisory Work Group and the Oregon Department of Human Services used NVDRS data to inform efforts to develop and focus suicide prevention programs for older adults. Almost 50% of men ages 65 and older who died by suicide were reported to have a depressed mood before death, but only a small proportion were receiving treatment, suggesting screening and treatment for depression might have saved lives. As a result, Oregon developed primary care recommendations in 2006 to better integrate with mental health services so that suicidal behavior and ideation are diagnosed and older adults received appropriate treatment. These recommendations were implemented as part of Oregon's "Healthy Aging" efforts. The recommendations include the objectives of increasing the confidence and competence of primary care providers and other clinicians to identify, assess and treat older adult suicide behavior and depression. The suicide rates among males ages 65 and older in Oregon decreased approximately eight percent from 2007 to 2010.

Safe States Alliance supports the investment of an additional $13.7 million to expand NVDRS to all states and territories.

PREVENTIVE HEALTH AND HEALTH SERVICES (PHHS) BLOCK GRANT

For more than 30 years, the PHHS Block Grant has remained an essential source of federal agencies to support state solutions to state health problems. The PHHS Block Grant allows each state to respond to its own distinct health priorities and need. In FY 2011, more than 20 percent of the Prevent Block Grant was used by states to support IVP and emergency medical services. According to a 2011 survey conducted by Safe States Alliance, 29 states reported receiving an average of $329,000 from the Prevent Block Grant for IVP efforts.[4] The Prevent Block Grant is a critical source of funding for SHD IVP programs representing 9.4 percent of total state funding in 2011. *Safe States Alliance supports continued funding of the PHHS Block Grant at the $180 million level.*

Preventable injuries exact a heavy burden on Americans through premature deaths and disabilities, pain and suffering, medical and rehabilitation costs, disruption of quality of life for families, and disruption of productivity for employers. Strengthening investments in public health IVP programs is a critical step to keep Americans safe and productive for the 21st century. Safe States Alliance would like to thank the Committee for consideration of this testimony.

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[1] National Research Council. Injury in America: A Continuing Public Health Problem. Washington, DC: The National Academies Press, 1985.
[2] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: http://www.cdc.gov/injury/wisqars.
[3] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: http://www.cdc.gov/injury/wisqars
[4] State of the States: 2011 Report. Atlanta, GA: Safe States Alliance; 2013.

WRITTEN TESTIMONY FOR THE RECORD
DR. IVY TURNBULL, DEPUTY EXECUTIVE DIRECTOR
AIDS ALLIANCE FOR WOMEN, INFANTS, CHILDREN, YOUTH & FAMILIES
TO THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES
HOUSE COMMITTEE ON APPROPRIATIONS
REGARDING THE FY 2015 BUDGET PROPOSAL CONSOLIDATING RYAN WHITE PART D FUNDING INTO PART C FUNDING OF THE PROGRAM

MARCH 28, 2014

Dear Chairman Kingston, Ranking Member DeLauro, and Members of the Subcommittee:

AIDS Alliance for Women, Infants, Children, Youth & Families was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk women, infants, children, youth, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. We are pleased to offer written testimony for the record in opposition of the FY 2015 budget proposal consolidating Ryan White Part D funding into Part C and in support of maintaining Part D of the Ryan White Program as part of the FY 2015 Labor, Health and Human Services, Education, and Related Agencies appropriations measure. This testimony also has the support of the Elizabeth Glaser Pediatric AIDS Foundation.

Ryan White Part D Funding Request

Sufficient funding of the Ryan White Program is necessary to provide quality care for individuals living with HIV/AIDS. We thank the Subcommittee for its continuous support of

Ryan White Part D Programs, providing $75 million to the program in FY 2014. While the AIDS Alliance for Women, Infants, Children, Youth & Families understands that these are difficult economic times, we are requesting the Subcommittee to maintain its commitment to the Ryan White Part D program and restore its funding eliminated in the President's FY 2015 budget proposal and increase Ryan White Part D funding by $9.9 million in FY 2015.

Ryan White Part D Background and History

Over concerns with the increase in the number of pediatric AIDS cases, Congress first acted to address pediatric cases in 1987 by providing $5 million for the Pediatric AIDS Demonstration Projects in the FY 1988 budget. Those demonstration projects became part of the Ryan White CARE Act of 1990 which today is known as Ryan White Part D and have served thousands of women, infants, children, youth and families. Since the program's inception in 1988, Part D programs have been and continue to be the entry point into medical care for women and youth and, in many communities or regions, Part D programs are the only perinatal clinical service available to serve HIV-positive pregnant women and youth when payments for such services are unavailable from other sources. Ryan White Part D programs have been extremely effective in bringing the most vulnerable populations into and retained in care and is the lifeline for women, infants, children and youth living with HIV/AIDS. The Part D programs are instrumental in preventing mother-to-child transmission of HIV and for ensuring that women, including HIV-positive pregnant women, HIV exposed infants, children and youth have access to quality HIV care. The program is built on a foundation of combining medical care and essential support services that are coordinated, comprehensive, and culturally and linguistically competent. This model of care addresses the health care needs of the most vulnerable populations living with HIV/AIDS in order to achieve optimal health outcomes.

In 2012, Part D provided funding to 114 community-based organizations, academic medical centers and hospitals, federally qualified health centers, and health departments in 39 states and Puerto Rico. These federally, directly-funded grantees provide HIV primary care, specialty and subspecialty care, oral health services, treatment adherence monitoring and education services pertaining to opportunities to participate in HIV/AIDS- related clinical research. These grantees also provide support services which include case management (medical, non-medical, and family-centered); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D grantees also receive assistance from other parts of the Ryan White Program that help support HIV testing and linkage to care services; provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model. This model has continuously provided comprehensive quality healthcare delivery systems that have been responsive to women, infants, children, youth and families for two decades.

A Response to Women, Infants, Children, and Youth

The Ryan White Program has been enormously successful in meeting its mission to provide life-extending care and services. Yet, even though we have made significant progress in decreasing HIV-related morbidity and mortality, much work remains to be done. While accounting for less that 6 percent of Ryan White direct care dollars (minus ADAP and Part F), Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, children, youth, and families. Part D funded programs played a leading role in reducing mother-to-child transmission of HIV-from as many as 2,000 babies born HIV positive

in 1990 to roughly 200 cases in 2010 through aggressive efforts to reach out to pregnant women. Appropriate funding is critical to maintain and improve upon this success, as there are still approximately 8,000 HIV-positive women giving birth every year in the United States that need counseling, services and support to prevent pediatric HIV Infections. According to the CDC, youth account for 39% of all new HIV infections in the U.S. As of 2010, one in four new HIV infections occur among young people ages 13-24. Most new HIV infections in youth (about 70 percent) occur in gay and bisexual males, most of whom are African Americans. Of the new HIV infections among youth, 2,100 are among young women; two-thirds of these are among young African American women. Ryan White Part D programs are the entry point into medical care for many HIV positive youth and leads the nation's effort in recruiting and retaining HIV positive youth to comprehensive medical care and support services. According to the Health Resources and Services Administration, more than 37 percent of women receiving medical care in Ryan White Programs do so through Part D. Additionally, Part D provides medical and supportive services to a large number of women over 50 who are heading into their senior years as HIV survivors which is a testament to the high standard of care provided to Ryan White Part D programs. Support and care through the Ryan White Part D program was and continues to be funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public health safety nets. Full implementation of the Affordable Care Act with continuation of the Ryan White Program will dramatically improve health access and outcomes for many more women, infants, children, and youth living with HIV disease.

Proposed Consolidation

The medical and supportive services provided by Ryan White Part D are unique and are not currently being provided by other parts of the Ryan White Program, including Ryan White Part

C. These services are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS. The proposed consolidation of Part D funding into Part C in the federal budget would eliminate a strong safety net for our most vulnerable populations and weaken the systems of care Part D programs have created and invested in for more than 25 years. Furthermore, the loss of Part D funds in some community areas would profoundly impact access to comprehensive HIV care and treatment for women, infants, children and youth. Many of the population served by Part D will be lost or never enter into care. We will not make progress in ending HIV/AIDS in this country without supporting all of the Parts of Ryan White.

Conclusion

These are difficult economic times, and we recognize the considerable fiscal constraints Congress faces in allocating limited federal dollars as well as the need to reduce administrative burdens associated with the overall operational aspects of Ryan White programs. However, it is unclear how the proposed consolidation of Part D funding into Part C of the program will be implemented to ensure the continuation of the delivery of life-saving HIV/AIDS care and treatment to the most vulnerable populations without destabilizing existing models of care created to address the unique needs of these populations. Without the Ryan White Part D program, many of these medically-underserved women, infants, children and youth would not receive the vital primary care and support services traditionally provided to them.

The AIDS Alliance for Women, Infants, Children, Youth & Families respectfully requests that the Subcommittee consider this written testimony for the record as you develop your FY 2015 appropriations bill. Thank you.

Jared Frost, Senior Associate, Legislative Affairs
American College of Physicians

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: FY2015 Budget, Department of Health and Human Services

March 25, 2014

The American College of Physicians (ACP) is pleased to submit the following statement for the record on its priorities, as funded under the U.S. Department of Health & Human Services, for FY2015. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 137,000 internal medicine physicians (internists), related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. As the Subcommittee begins deliberations on appropriations for FY2015, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

- Title VII, Section 747, Primary Care Training and Enhancement, at no less than $71 million;
- National Health Service Corps, $810 million in funding, including the $310 million in enhanced funding through the Community Health Centers Fund;
- National Health Care Workforce Commission, $3 million;
- Agency for Healthcare Research and Quality, $375 million; and
- Centers for Medicare and Medicaid Services, Program Management for Marketplaces, $629 million.

The United States is facing a growing shortage of physicians in key specialties, most notably in general internal medicine and family medicine—the specialties that provide primary care to most adult and adolescent patients. With enactment of the Affordable Care Act (ACA), we expect the demand for primary care services to increase with the addition of 25 million Americans receiving access to health insurance, including an additional 13 million under Medicaid/CHIP, once the law is fully implemented. With increased demand, current projections indicate there will be a shortage of over 45,000 primary care physicians by 2020, growing to a shortage of over 65,000 primary care physicians by 2025. (AAMC Center for Workforce Studies with the Lewin Group. The Impact of Health Care Reform on the Future Supply and Demand of Physicians Updated Projections Through 2025. June 2010. Accessed at: https://www.aamc.org/download/158076/data/updated_projections_through_2025.pdf). Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with **over 100 studies showing primary care is associated with better outcomes and lower costs of care** (http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf).

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 in helping institutions and programs respond to the current and emerging challenges of ensuring that all Americans have

access to appropriate and timely health services. Within the Title VII program, we urge the Subcommittee to fund the **Section 747, Primary Care Training and Enhancement** program at $71 million, in order to maintain and expand the pipeline for individuals training in primary care. 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 emphasizing interdisciplinary training that have helped prepare them to work with other health professionals, such as physician assistants, patient educators, and psychologists. Without a substantial increase in funding, for the fourth year in a row, HRSA will not be able to carry out a competitive grant cycle for physician training; the nation needs new initiatives supporting expanded training in multi-professional care, the patient-centered medical home, and other new competencies required in our developing health system.

The College urges $810 million in funding for the **National Health Service Corps** (NHSC), as requested in the President's FY2015 budget; this amount includes the $310 million in enhanced funding the Health and Human Services Secretary has been given the authority to provide to the NHSC through the Community Health Centers Fund. Since the enactment of the ACA, the NHSC has awarded over $1 billion in scholarships and loan repayment to health care professionals to help expand the country's primary care workforce and meet the health care needs of underserved communities across the country. With field strength of nearly 9,000 clinicians, NHSC members are providing culturally competent care to more than 10.4 million people at nearly 14,000 NHSC-approved health care sites in urban, rural, and frontier areas. The increase in funds would expand NHSC field strength to 15,000 and would serve the needs of

more than 16 million patients, helping to address the health professionals' workforce shortage and growing maldistribution. The programs under NHSC have proven to make an impact in meeting the health care needs of the underserved, and with increased appropriations, they can do more.

We urge the Subcommittee to fully fund the **National Health Care Workforce Commission**, as authorized by the ACA, at $3 million. 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 polices. Members of the Commission have been appointed, but have not begun work due to a lack of funding. The College believes the nation needs a comprehensive workforce policy founded on sound research to determine the nation's current and future needs for 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 **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, clinicians, 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 recommends a budget of $375 million. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, fund research that serves as the evidence engine for much of the private sector's work

to keep patients safe, make the healthcare market place more efficient by providing quality measures to health professionals, and ultimately, help transform health and health care.

Finally, ACP supports $629 million in funding for the **Centers for Medicare and Medicaid Services, Program Management for Marketplaces** as requested in the President's FY2015 budget in order to carry out its duties as necessary. Such funding would allow the federal government to continue to administer the insurance marketplaces as authorized by the ACA if a state has declined to establish an exchange that meets federal requirements. CMS now manages and operates some or all marketplace activities in over 30 states. If the Subcommittee decides to deny the requested funds, it will be much more difficult for the federal government to operate and manage a federally-facilitated exchange in those states, raising questions about where and how their residents would obtain and maintain coverage. It is ACP's belief that all legal Americans – regardless of income level, health status, or geographic location – must have access to affordable health insurance.

In conclusion, 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 primary care workforce and 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 FY2015 appropriations process.

Timothy DeRouen, PhD, President (2014-2015)
American Association for Dental Research, Public Witness Testimony
House Labor, Health and Human Services and Education Appropriations Subcommittee
March 28, 2014

On behalf of the 3,500 individual and 44 institutional members of the American Association for Dental Research (AADR), I am pleased to submit testimony describing AADR's fiscal year 2015 requests, which include **$32 billion for the National Institutes of Health (NIH) and $425 million for the National Institute of Dental and Craniofacial Research (NIDCR).** These funding recommendations represent the true needs of the research community while at the same time taking into consideration the continued tight budget climate dictated by the caps established by the *Bipartisan Budget Act of 2013*. I want to emphasize the recent federal austerity measures–sequestration, government shutdown and the continued uncertainty–had a significant impact on our members, universities and research supported via NIDCR. In actual dollars, NIDCR lost $23 million in funding in fiscal year 2013 and only $10 million was restored in fiscal year 2014. However, when adjusted for inflation, the NIDCR budget is 22 percent, or $75 million, less than it was in 2002, resulting in the lowest number of research grants awarded in 13 years. This creates an atmosphere that is very discouraging to new scientific investigators whose research proposals are good enough to be funded but were not because of the budget cuts. We are at risk of losing them and their promising research ideas—ideas that might lead to significant advances in dental, oral health and craniofacial health.

The downward trend in lost purchasing power is particularly troubling because the improvements in oral health during the last half century are largely credited to research supported by NIDCR. It is therefore reasonable to assume that these declines in funding will

slow or limit future breakthroughs. NIDCR is the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial health. The health of the mouth and surrounding craniofacial (skull and face) structures is central to a person's overall health and well-being. Left untreated, oral diseases and poor oral conditions go untreated, make it difficult to eat, drink, swallow, smile, talk and maintain proper nutrition. Scientists also have discovered important linkages between gum disease, or periodontal disease, and heart disease, stroke, diabetes and pancreatic cancer.

In spite of these improvements, however, treating oral health conditions is costly with $110.9 billion in expenditures on dental services in 2012. While tooth decay and gum disease remain the most prevalent, complete tooth loss, oral cancer, and craniofacial congenital anomalies, like cleft lip and palate are also health and economic burdens to the American people. Moreover, oral health disparities exist for many racial and ethnic groups. By providing **$425 million** in fiscal year 2015, NIDCR, dental, oral and craniofacial researchers will be able to build upon the gains of the past decades, creating less invasive, cost effective and more efficient ways to improve oral health. Below are some examples highlighting the important work supported by NIDCR:

- **Point of Care Diagnostics:** Salivary diagnostics are measures that draw and analyze saliva to test for conditions such as HIV, HPV, substance abuse, caries, periodontitis and oral cancer. Through the work and support of NIDCR over the last decade, these diagnostics are showing great promise in screening for diabetes, heart disease, lung cancer, ovarian cancer and pancreatic cancer. Salivary diagnostics only require withdrawing saliva, unlike traditional methods that rely on withdrawing blood or on doing tissue biopsy. As a result, salivary diagnostics are less invasive. In addition, they are

relatively inexpensive and have the potential of showing more immediate results which is particularly beneficial when results are urgently needed.

- **Periodontal Disease:** Periodontal or gum disease is a chronic inflammatory disease that affects the gum tissue and bone supporting the teeth. Approximately 47.2 percent of Americans have mild, moderate or severe periodontitis. If left untreated, periodontal disease can lead to tooth loss. Research has shown that periodontal disease is associated with other chronic inflammatory diseases such as diabetes and cardiovascular disease. To date, the prevention of gum disease has been limited to successful oral hygiene and regular professional care. Recently, however, scientists reported the discovery of resolvins, a biologically active product that has the potential to protect against soft tissue and bone loss associated with gum disease. More research is needed to further intensify efforts to apply the novel biological approach to treating inflammatory diseases.
- **Dental Caries**: Dental caries, or tooth decay, remains the most prevalent chronic disease in both children and adults resulting in a substantial economic and health burden to the American people. Although caries has significantly decreased for most Americans over the past four decades, disparities remain among some population groups. In addition, this downward trend has recently reversed for young children. More research is needed to enhance efforts to address dental caries.
- **HPV-Related Oral Cancer:** This type of cancer is caused by the human papillomavirus (HPV). It is predicted that this cancer will be the most common HPV-related cancer by 2020. HPV-induced oral cancers among men are likely to exceed HPV-induced cervical cancers within the next eight years. In fact, HPV is now causing more

oral cancers than smoking. Identifying the presence of HPV in a mouth swab or a blood draw does not definitively indicate the impending presence of cancer. As a result, more research is needed for the early detection of HPV-related oral cancer, and for the development of therapies that would lead to the prevention of cancer progression.

- **Evidenced-Based Practice**: NIDCR recently awarded a seven-year grant that consolidates its dental practice-based research network initiative into a unified nationally coordinated effort. The consolidated initiative, the National Dental Practice Based Research Network (NDPBRN) is headquartered at the University of Alabama at Birmingham School of Dentistry. A dental practice-based research network is an investigative union of practicing dentists and academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address daily issues in oral health care. These studies help to expand the profession's evidence base and further refine care.
- **Cleft Lip and/or Cleft Palate** – Craniofacial anomalies such as cleft lip and/or cleft palate (CLP) are among the most common birth defects. Both genetic and environmental factors contribute to oral clefts. Cleft lip is an abnormality in which the lip does not completely form during fetal development and cleft palate occurs when the roof of the mouth does not fully close, leaving an opening that can extend into the nasal cavity. Genome-wide association studies (GWAS) of cleft lip and/or cleft palate supported by NIDCR are providing important new leads about the role genetic factors and gene-environment interactions play in the development of these conditions. In addition, a DNA sequencing study is underway to identify less common genetic variants that influence the risk of developing cleft lip and/or cleft palate. NIDCR will continue to

support the best science to understand craniofacial structures and anomalies more completely.

Our members remain concerned that unless Congress fully reverses the erosion caused by sequestration our ability to attract the next generation of scientists will stall; our standing as a world leader in science will decline; and innovation necessary to push the boundaries of research will be stymied. Accordingly, I strongly urge you work in a bipartisan manner to prioritize funding for dental, oral and craniofacial research this year and undo sequestration permanently in fiscal year 2016 and beyond. Future advances in health care depend on a sustained investment in basic research to identify the fundamental causes and mechanisms of disease, accelerate technological development and discovery, and ensure a robust pipeline of creative and skillful biomedical researchers. For these reasons, I implore you to work in a bipartisan manner and provide funding increases for NIH and NIDCR in fiscal year 2015.

In addition to the NIH, AADR members care deeply about the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce; the Centers for Disease Control and Prevention (CDC) Division of Oral Health's public health prevention efforts; data from the National Center for Health Statistics (NCHS) and the Agency for Healthcare Research & Quality (AHRQ). Please support AADR's funding recommendations for these agencies depicted in the chart below.

In Millions of Dollars

Agency	**FY12**	**FY13**	**FY14**	**FY15 PBR**	**FY15 AADR**
NIH	**30,702**	**29,070**	**30,020**	**30,220**	**32,000**
NIDCR	**410.3**	**386.8**	**397.10**	**397.13**	**425.0**
NCATS	574.8	542.1	633.3	657.5	657.5
AHRQ	405.1	429.4	364	334	375
CDC, Oral Health	14.6	13.8	15.8	15.8	19.0
CDC, NCHS	153.8	153.8	155.3	155.4	182
HRSA, Title VII Oral Health	32.4	30.7	32	32	32.4

MARCH 27, 2014

Written Testimony for the Record submitted by:

Mary A. Vitale, Guardian/Sibling/Advocate

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

Subject: 2015 Budget of Department of Health and Human Services

Amount of Funding: 71 million for State Councils on Disability and 44 million for Protection and Advocacy Programs –as stated in the HHS 2015 Budget

Request: Review the misuse of Federal Funds by HHS Programs to promote forced deinstitutionalization of persons with severe, profound intellectual and developmental disabilities.

Dear Committee Members on Labor, Health and Human Services, Education and Related Agencies:

The opportunity to submit personal testimony to this committee is much appreciated. As HHS budget requests are being considered, this submission of testimony is a request for a review of the misuse of federal funds by some HHS programs that promote forced deinstitutionalization of persons with severe and profound intellectual and developmental disabilities.

I have been an active legal guardian for 35 years for my brother who has severe intellectual disabilities, behavior challenges, and multiple physical impairments. His home is an intermediate care facility for individuals with intellectual disabilities (ICF/IID). I am grateful that some HHS funds are helping persons with intellectual disabilities. However, in many states, some of the funds are being misused to promote the closing ICF/IID homes.

ICF/IID homes are called habilitation centers in Missouri. Some Missouri examples of misuse of HHS funds that promote forced closing of habilitation centers include the following:

1. The 2012-16 Missouri Planning Council Five Year Plan includes in Objective 7: "By 9/30/16 at least three of the six state-run habilitation centers will close." This is being done without input of guardians of residents of habilitation centers.

2. The Missouri Planning Council testifies at State hearings in support of closing habilitation centers, using questionable cost estimates.

3. The Missouri and Protection and Advocacy agency sent out letters to families of residents of habilitation centers stating that abuse was happening. In fact there was no abuse being investigated. Their interpretation of abuse for this letter was: If you live in a habilitation center, that is abuse. Families were appalled at the scare tactics in order to get residents to move. The Missouri Department of Mental Health sent a letter of reprimand to Missouri P&A.

4. The Missouri Planning Council had an ad in the St. Louis Post-Dispatch saying residents of habilitation centers were being held in prisons by their family members because they lived in a habilitation center. This was also on the website for several years.

These are clear examples of these HHS programs **misusing federal funds** by going far astray from their original intent of protection of persons with intellectual disabilities. These misguided activities by HHS programs negatively affect every part of the daily lives of persons diagnosed with severe and profound intellectual disabilities, who many times also have multiple physical impairments, extreme behavior challenges, and complex medical concerns. These actions are putting the safety, health, and well-being of our family members at risk.

The Supreme Court 1999 *Olmstead* ruling states: "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."

This is exactly what is happening across the United States by the misuse of some of the HHS funds. Appropriate cost-effective care for those with the severest disabilities is available in ICF/IID homes, and yet they are targeted for closure, ignoring the educated choice of guardians/family members. Many community settings have too little assistance and too little supervision to be appropriate for those with multiple intellectual and physical impairments.

I ask each member of this committee to seriously question the funding of those HHS programs that engage in promoting total deinstitutionalization for persons with intellectual disabilities. Help us keep our family members safe and healthy.

Respectfully,

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House Committee on Appropriations
Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
2358-B Rayburn House Office Building
Washington, DC 20515

March 28, 2014

Dear Subcommittee on Labor, Health and Human Services, Education and Related Agencies:

The Academy of Nutrition and Dietetics appreciates the opportunity to submit testimony for the Fiscal Year 2015 appropriations. The Academy is the world's largest organization of food and nutrition professionals, and is committed to improving the nation's health with nutrition services and interventions provided by registered dietitian nutritionists. Nationwide, The Academy has over 75,000 members.

As Congress begins work on Fiscal Year 2015 appropriations, we strongly urge you to fully fund federal nutrition programs that will provide a return on investment to improve health. Investment in these programs through the appropriations process will help prevent costly health care expenses due to chronic diseases.

Senior Nutrition Funding: Administration for Community Living (ACL)

The congregate and home-delivered (commonly known as Meals on Wheels) senior nutrition programs, the Native American Nutrition Program, and the Nutrition Services Incentive Program (NSIP) are the largest and most visible components of the Older Americans Act. We strongly believe that the funding levels for the senior nutrition programs under the Administration for Community Living must be adequate, as these programs are key to keeping this population

independent and in their homes. The President's budget proposes no increase for the senior nutrition programs in FY 2015, yet we know that fuel and food costs – primary costs borne by senior nutrition programs – continue to increase. This is extremely alarming as these programs ensure that vulnerable older adults can continue to receive cost-effective nutrition services, ultimately saving Medicare and Medicaid dollars. Due to an ever-increasing demand for services, even flat funding will result in several million fewer home-delivered and congregate meals served, which could lead to more expensive hospitalizations or a need for long term care for older adults who cannot safely prepare meals themselves.

The Academy strongly supports the President's FY 2015 request for $20 million for Preventive Health Services under the Older Americans Act. This program provides grants to States and Territories to support activities that educate older adults about the importance of health lifestyles and promotes healthy behaviors that can help to prevent or delay chronic disease and disability, thereby reducing the need for costly medical interventions.

The Academy also supports the Administration's proposal for standalone funding of $8 million for Chronic Disease Self-Management Programs (CDSMP) in the Administration for Community Living. CDSMP is a low-cost, evidence-based disease prevention model that utilizes state-of-the-art techniques to help older Americans with chronic diseases better manage their conditions and improve their health status, thus reducing their need for more costly medical care such as hospital care and hospital readmissions. According to the National Center for Chronic Disease Prevention and Promotion, seven out of ten deaths and more than three-quarters

of all health expenditures for older adults are the result of preventable chronic conditions such as diabetes, obesity, cancer, arthritis and depression.

In addition, the Academy supports the President's FY 2015 request for $25 million in funding for the Elder Justice Act. Cases of elder abuse, neglect and exploitation are on the rise in this country; recent studies estimate that 14.1 percent of older adults face some sort of abuse, and another study estimates seniors lose a minimum of $2.5 billion each year as a result (MetLife and the National Committee for the Prevention of Elder Abuse). Elder abuse is a major threat to the health of our elderly population.

Centers for Disease Control and Prevention (CDC) Funding

The Academy respectfully requests adequate funding for CDC's FY 2015 "core programs." We strongly believe that the activities and programs supported by CDC are essential to protect the health of the American people. CDC is faced with enormous challenges and responsibilities, from bioterrorism preparedness to chronic disease prevention and eliminating health disparities. In addition, CDC funds effective community programs including health promotion efforts and nutrition interventions that help prevent heart and lung disease, cancer, diabetes, stroke, and other chronic diseases. More than 70% of CDC's budget supports state and local health organizations and academic institutions.

We support the President's budget proposal to reduce chronic diseases through diabetes funding totaling $140 million and heart disease funding totaling $130 million. These expenditures will help reduce the heavy health care cost burden of these two diseases.

We also ask that you maintain the FY 2014 funding of $8 million (not the reduced level in the FY 2015 President's Request) for Hospitals Promoting Breastfeeding. According to the CDC, childhood obesity is an epidemic. One in five preschoolers in our country is overweight, and half of these are obese. A baby's risk of becoming an overweight child is reduced with each month that the baby is breastfed. In the US, most babies start breastfeeding, but within the first week, half have already been given formula, and by 9 months, only 31% of babies are breastfeeding at all. Hospitals play a critical role in encouraging new moms to breastfeed.

Food and Drug Administration (FDA) Funding

The Academy supports the President' budget of $1.48 billion for food safety. A robust food safety system and the continued implementation of the Food Safety Modernization Act will help reduce food-borne illness that costs the U.S. health care system $88 billion annually.

Again, thank you for reviewing these comments and please feel free to contact us for any additional information.

Respectfully Submitted,

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SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES

ON THE
FISCAL YEAR 2015
DEPARTMENT OF HEALTH AND HUMAN SERVICES APPROPRIATIONS

March 15, 2014

SUMMARY OF FY14 RECOMMENDATIONS

1) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF $1 BILLION OVER FY 2014. INCREASE FUNDING FOR THE NATIONAL CANCER INSTITUTE (NCI), THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) AND THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID) BY 12%.**

2) **CONTINUE FOCUS ON DIGESTIVE DISEASE RESEARCH AND EDUCATION AT NIH, INCLUDING INFLAMMATORY BOWEL DISEASE (IBD), HEPATITIS AND OTHER LIVER DISEASES, IRRITABLE BOWEL SYNDROME (IBS), COLORECTAL CANCER, ENDOSCOPIC RESEARCH, PANCREATIC CANCER, AND CELIAC DISEASE.**

3) **$50 MILLION FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION'S (CDC) HEPATITIS PREVENTION AND CONTROL ACTIVITIES.**

4) **$50 MILLION FOR THE CENTER FOR DISEASE CONTROL AND PREVENTION'S (CDC) COLORECTAL CANCERSCREENING AND PREVENTION PROGRAM.**

Chairman Kingston, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC) is a voluntary health organization comprised of 35 professional societies and patient organizations concerned with the many diseases of the digestive tract. The DDNC promotes a strong federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing

disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, and Celiac Disease.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at $60 billion a year.

The DDNC would like to thank the Subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the DDNC recommends:

- 32 billion for the NIH.
- $2.16 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

INFLAMMATORY BOWEL DISEASE

In the United States today about one million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious

diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium to continue its work in IBD research. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to continue to support a nationwide IBD surveillance and epidemiological program in FY15.

VIRAL HEPATITIS: A LOOMING THREAT TO HEALTH

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of state health departments, particularly to enhance resources available to the hepatitis state coordinators. The DDNC also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

The DDNC supports $50 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis

Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The DDNC recommends a funding level of $50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

PANCREATIC CANCER

In 2013, an estimated 33,730 people in the United States will be found to have pancreatic cancer and approximately 32,300 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only lout of 4 patients will live one year after the cancer is found and only 1 out of 25 will survive five or more years.

The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

IRRITABLE BOWEL SYNDROME (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

The DDNC recommends that NIDDK increase its research portfolio on Functional Gastrointestinal Disorders and Motility Disorders.

CONCLUSION

The DDNC understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

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REGARDING FISCAL YEAR 2015 APPROPRIATIONS FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION AND THE NATIONAL INSTITUTES OF HEALTH

SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS; SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

MARCH 15, 2014

SUMMARY OF FY15 RECOMMENDATIONS

1) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF $1 BILLION OVER FY 2014.**

2) **CONTINUED FOCUS ON HEREDITARY ANGIOEDEMA RESEARCH AND EDUCATION AT NIH**

3) **FUNDING TO CREATE AND SUPPORT THE CENTERS FOR DISEASE CONTROL AND PREVENTION'S (CDC) TO INCREASE AWARENESS EFFORTS FOR HEREDITARY ANGIOEDEMA AT CDC**

Chairman Kingston, thank you for the opportunity to present the views of the US Hereditary Angioedema Association (US HAEA) regarding the importance of Hereditary Angioedema (HAE) public awareness activities and research.

The US HAEA is a non-profit patient advocacy organization founded in 1999 to help those suffering with HAE and their families to live healthy lives. The Association's goals were, and remain, to provide patient support, advance HAE research and find a cure. The US HAEA provides patient services that include referrals to HAE knowledgeable health care providers,

disease information and peer-to-peer support. US HAEA also provides research funding to scientific investigators to increase the HAE knowledge base and maintains an HAE patient registry to support ground-breaking research efforts. Additionally, US HAEA provides disease information materials and hosts forums to educate patients and their families, health care providers, and the general public on HAE.

HAE is a rare and potentially life-threatening inherited disease with symptoms of severe, recurring, debilitating attacks of edema (swelling). HAE patients have a defect in the gene that controls a blood protein called C1-inhibitor, so it is also more specifically referred to as C1-inhibitor deficiency. This genetic defect results in production of either inadequate or nonfunctioning C1-inhibitor protein. Because the defective C1-inhibitor does not adequately perform its regulatory function, a biochemical imbalance can occur and produce an unwanted peptide — called bradykinin — that induces the capillaries to release fluids into surrounding tissues, thereby causing swelling.

People with HAE experience attacks of severe swelling that affect various body parts including the hands, feet, face, airway (throat) and intestinal wall. Swelling of the throat is the most life-threatening aspect of HAE, because the airway can close and cause death by suffocation. Studies reveal that more than 50 percent of patients will experience at least one throat attack in their lifetime.

HAE swelling is disfiguring, extremely painful and debilitating. Attacks of abdominal swelling involve severe and excruciating pain, vomiting, and diarrhea. Because abdominal attacks mimic a surgical emergency, approximately one third of patients with undiagnosed HAE undergo unnecessary surgery. Untreated, an average HAE attack lasts between 24 and 72 hours, but some attacks may last longer and be accompanied by prolonged fatigue.

The majority of HAE patients experience their first attack during childhood or adolescence. Most attacks occur spontaneously with no apparent reason, but anxiety, stress, minor trauma, medical, surgical, and dental procedures, and illnesses such as colds and flu have been cited as common triggers. ACE Inhibitors (a blood pressure control medication) and estrogen-derived medications (birth control pills and hormone replacement drugs) have also been shown to exacerbate HAE attacks.

HAE's genetic defect can be passed on in families. A child has a 50 percent chance of inheriting the disease from a parent with HAE. However, the absence of family history does not rule out the HAE diagnosis; scientists report that as many as 25 percent of HAE cases today result from patients who had a spontaneous mutation of the C1-inhibitor gene at conception. These patients can also pass the defective gene to their offspring. Worldwide, it is estimated that this condition affects between 1 in 10,000 and 1 in 30,000 people.

PUBLIC AWARENESS AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

HAE patients often suffer for many years and may be subject to unnecessary medical procedures and surgery prior to receiving an accurate diagnosis. Raising awareness about HAE among healthcare providers and the general public will help reduce delays in diagnosis and limit the amount of time that patients must spend without treatment for a condition that could, at any moment, end their lives.

Once diagnosed, many individuals are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, over many years, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these patients understand that HAE often requires

emergency treatment and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, intelligent use of available treatments can help patients lead a productive life.

In order to prevent deaths, eliminate unnecessary surgeries, and improve patients' quality of life, it is critical that CDC pursue programs to educate the public and medical professionals about HAE in fiscal year 2015.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

In years past, HAE research was conducted at the National Institutes of Health (NIH) through the National Institute of Allergy and Infectious Diseases, the National Institute of Neurological Disorders and Stroke, the National Heart Lung and Blood Institute, the National Institute of Child Health and Human Development, National Center for Research Resources, and the National Institute on Diabetes and Digestive and Kidney Diseases. However, NIH has not engaged in HAE-specific research since 2009, and there is no longer any federal research as it relates to HAE.

As it may provide greater opportunities for HAE research, we applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Housing translational research activities at a single Center at NIH will allow these programs to achieve new levels of success. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposing have the potential to speed access to new treatments, particularly to patients who struggle with rare or neglected diseases. As a rare disease community, HAE patients may also benefit from the Therapeutics for Rare and Neglected Diseases (TRND) program, housed at NCATS, as well

coordination with the Office of Rare Diseases Research (ORDR). We ask that you support NCATS and provide adequate resources for the Center in fiscal year 2014.

In order to reinvigorate HAE research at NIH, it is vital that NIH receive increased support in fiscal year 2015. US HAEA recommends an overall funding level of $32 billion for NIH in fiscal year 2015 and the inclusion of recommendations emphasizing the importance of HAE research to learn more about this rare disease and new pathways for appropriate treatment.

Thank you for the opportunity to present the views of the HAE community.

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REGARDING FISCAL YEAR 2015 APPROPRIATIONS
FOR THE NATIONAL INSTITUTES OF HEALTH

SUBMITTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

MARCH 15, 2014

1) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF $1 BILLION OVER FY 2012. INCREASE FUNDING FOR THE NATIONAL CANCER INSTITUTE (NCI), THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) AND THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID) BY 12%.**

2) **CONTINUE FOCUS ON DIGESTIVE DISEASE RESEARCH AND EDUCATION AT NIH, INCLUDING), IRRITABLE BOWEL SYNDROME (IBS), FECAL INCONTINENCE GASTROESOPHAGEAL REFLUX DISEASE (GERD) GASTROPARESIS, AND CYCLIC VOMITING SYNDROME (CVS).**

Thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of functional gastrointestinal and motility disorders (FGIMD) research. Established in 1991, IFFGD is a patient-driven nonprofit organization dedicated to assisting individuals affected by FGMIDs, and providing education and support for patients, healthcare providers, and the public. IFFGD also works to advance critical research on FGIMDs in order to develop better treatment options and to eventually find cures. IFFGD has worked closely with the National Institutes of Health (NIH) on many priorities, and I served on the National Commission on Digestive Diseases (NCDD), which released a long-range plan in 2009, entitled *Opportunities and Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases.*

The need for increased research, more effective and efficient treatments, and the hope for discovering a cure for FGIMDs are close to my heart. My own experiences of suffering from FGIMDs motivated me to establish IFFGD, and I was shocked to discover that despite the high prevalence of FGIMDs among all demographic groups, such a lack of research existed. This translates into a dearth of diagnostic tools, treatments, and patient supports. Even more shocking is the lack of awareness among the medical community and the public, leading to significant delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary surgery. Most FGIMDs have no cure and limited treatment options, so patients face a lifetime of chronic disease management. The costs associated with these diseases range from $25-$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

IRRITABLE BOWEL SYNDROME (IBS)

IBS affects 30 to 45 million Americans, conservatively at least 1 out of every 10 people. It is a chronic disease that causes 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 diagnostic test, IBS often goes undiagnosed or misdiagnosed for years. Even after IBS is identified, treatment options are limited and vary from patient to patient. Due to persistent pain and bowel unpredictability, individuals may distance themselves from social events and work. Stigma surrounding bowel habits may act as barrier to treatment, as patients are not comfortable discussing their symptoms with doctors. Many people also dismiss their symptoms or attempt to self-medicate with over-the-counter medications. Outreach to physicians and the general public remain critical to overcome these barriers to treatment and assist patients.

FECAL INCONTINENCE

At least 12 million Americans suffer from fecal incontinence. Incontinence crosses all age groups, but is more common among women and the elderly of both sexes. Often it is associated with neurological diseases, cancer treatments, spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, and uterine cancer. Causes of fecal incontinence include: 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. People may feel ashamed or humiliated, and most attempt to hide the problem for as long as possible. Some don't want to leave the house in fear they might have an accident in public; they withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly is the primary reason for nursing home admissions, an already significant social and economic burden in our aging population. In 2002, IFFGD sponsored a consensus conference entitled, *Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities.* IFFGD also collaborated with NIH on the *NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults* in 2007.

NIDDK recently launched a Bowel Control Awareness Campaign (BCAC) that provides resources for healthcare providers, information about clinical trials, and advice for individuals suffering from bowel control issues. The BCAC is an important step in reaching out to patients, and we encourage continued support for this campaign. Further research on fecal incontinence is critical to improve patient quality of life and implement the research goals of the NCDD.

GASTROESOPHAGEAL REFLUX DISEASE (GERD) GERD is a common disorder which results from the back-flow of stomach contents into the esophagus. GERD is often accompanied

by chronic heartburn and acid regurgitation, but sometimes the presence of GERD is only revealed when dangerous complications become evident. There are treatment options available, but they are not always effective and may lead to serious side effects. Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year and even more premature infants. GER results from immature upper gastrointestinal motor development. Up to 8% of children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction 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, and is 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. In many patients the cause cannot be found and the disorder is termed idiopathic gastroparesis.

CYCLIC VOMITING SYNDROME (CVS)

CVS is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea and vomiting, accompanied by abdominal pain, prostration, and lethargy, last hours to days. Previously thought to occur primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in many age groups, including adults. CVS patients often go for years without correct diagnosis. CVS leads to significant time lost from school and from work, as well as substantial

medical morbidity. The cause of CVS is not known. Research 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 $32 billion for FY 2015. Strengthening and preserving our nation's biomedical research enterprise fosters economic growth and supports innovations that enhance the health and well-being of the nation. Concurrent with overall NIH funding, IFFGD supports the growth of research activities on FGIMDs to strengthen the medical knowledge base and improve treatment, particularly through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Such support would expedite the implementation of recommendations from the NCDD. It is also vital for NIDDK to work with the National Institute of Child Health and Human Development (NICHD) to expand its research on the impact FGIMDs have on pediatric populations. Following years of near level-funding, research has been negatively impacted across all NIH Institutes and Centers. Without additional funding, medical researchers run the risk of losing promising research opportunities that could benefit patients.

We applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposement hold the potential to speed new treatment to patients. We ask that you support NCATS and provide adequate resources for the Center in FY 2015.

Thank you for the opportunity to present these views on behalf of the FGIMD community.

STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA
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SUBMITTED TO THE HOUSE COMMITTEE ON APPROPRIATIONS;
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES

ON THE
FISCAL YEAR 2015
DEPARTMENT OF HEALTH AND HUMAN SERVICES APPROPRIATIONS

March 20, 2014

SUMMARY OF FY14 RECOMMENDATIONS

1) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH) AT AN INCREASE OF $1 BILLION OVER FY 2014. INCREASE FUNDING FOR THE NATIONAL CANCER INSTITUTE (NCI), THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) AND THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID) BY 12%.**

2) **CONTINUED FOCUS ON DIGESTIVE DISEASE RESEARCH AND EDUCATION AT NIH, INCLUDING INFLAMMATORY BOWEL DISEASE (IBD) AND COLORECTAL CANCER.**

3) **$6860,000 FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION'S (CDC) IBD EPIDEMIOLOGY ACTIVITIES.**

4) **$50 MILLION FOR THE CENTER FOR DISEASE CONTROL AND PREVENTION'S (CDC) COLORECTAL CANCERSCREENING AND PREVENTION PROGRAM.**

Thank you for the opportunity to submit testimony to the Subcommittee. CCFA has remained committed to its mission of finding a cure for Crohn's disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases for over 46 years. Impacting an estimated 1.4 million Americans, 30% of whom are diagnosed in their

childhood years, Inflammatory Bowel Diseases (IBD) are chronic disorders of the gastrointestinal tract which cause abdominal pain, fever, and intestinal bleeding. IBD represents a major cause of morbidity from digestive illness and has a devastating impact on both patients and their families.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at $60 billion a year.

The CCFA would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the CCFA recommends:

- $32 billion for the NIH.
- $2.16 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the CCFA respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the CCFA would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

INFLAMMATORY BOWEL DISEASE

In the United States today about one million people suffer from Crohn's disease and ulcerative colitis, collectively known as IBD. These are serious diseases

that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The CCFA encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The CCFA urges the Consortium to continue its work in IBD research.

CENTERS FOR DISEASE CONTROL AND PREVENTION IBD EPIDEMIOLOGY

CDC, in collaboration with a nationwide, geographically diverse network of large managed health care delivery systems, has led an epidemiological study of IBD to understand IBD incidence, prevalence, demographics, and healthcare utilization. The group, comprised of investigators at the Massachusetts General Hospital in Boston, Rhode Island Hospital, the Crohn's and Colitis Foundation of America, and CDC, has piloted the Ocean State Crohn's and Colitis Registry (OSCAR), which includes both pediatric and adult patients. Since 2008, the OSCAR investigators have recruited 22 private-practice groups and hospital based physicians in Rhode Island and are that enrolling newly diagnosed patients into the registry. This study found an average annual incidence rate of 8.4 per 100,000 people for Crohn's disease and 12.4 per 100,000 for Ulcerative Colitis; published in Inflammatory Bowel Disease Journal, April 2007.

- Over the course of the initial 3-year epidemiologic collaboration, CDC laboratory scientists and epidemiologists worked to improve detection tools and

epidemiologic methods to study the role of infections (infectious disease epidemiology) in pediatric IBD, collaborating with extramural researchers who were funded by a National Institutes of Health (NIH) research award.

- Since 2006, CDC epidemiologists have been working in conjunction with the Crohn's and Colitis Foundation of American and a large health maintenance organization to better understand the natural history of IBD and factors that predict the course of disease.

The Crohn's and Colitis Foundation of America encourages the CDC to continue to support a nationwide IBD surveillance and epidemiological program in FY14.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The CCFA recommends a funding level of $50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

CONCLUSION

The CCFA understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC.

Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of our patients, we appreciate your consideration of our view. We look forward to working with you and your staff.

TESTIMONY ON BEHALF OF THE MARCH OF DIMES FOUNDATION

Contact: Emil Wigode Director, Federal Affairs
March of Dimes, ewigode@marchofdimes.com, (202) 659-1800

MARCH OF DIMES: FY 2015 FEDERAL FUNDING PRIORITIES (Dollars in Thousands)

PROGRAM	FY 2015 REQUEST
National Institutes of Health (Total)	**32,000,000**
National Institute of Child Health and Development	1,370,000
National Human Genome Research Institute	536,967
National Institute on Minority Health and Disparities	289,426
Centers for Disease Control and Prevention (Total)	**7,800,000**
National Center for Birth Defects and Developmental Disabilities	139,000
Birth Defects Research and Surveillance	22,300
Folic Acid Campaign	2,800
Immunizations	720,000
Polio Eradication	146,000
Safe Motherhood Initiative	46,000
Preterm Birth	2,000
National Center for Health Statistics	182,000
Health Resources and Services Administration (Total)	**7,480,000**
Title V, Maternal and Child Health Block Grant	639,000
SPRANS- Infant Mortality and Preterm Birth	3,000
Heritable Disorders	18,000
Universal Newborn Hearing	18,660
Healthy Start	103,532
Children's Hospitals Graduate Medical Education	300,000
Agency for Healthcare Research and Quality (Total)	**375,000**

The three million volunteers and 1,200 staff members of the March of Dimes Foundation appreciate the opportunity to submit federal funding recommendations for Fiscal Year 2015 (FY15). The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with chapters in every state, the District of Columbia and Puerto Rico. The March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in maternal and child health.

PRETERM BIRTH

Preterm birth is a serious health problem that costs the United States more than $26 billion annually. Employers, private insurers and individuals bear approximately half of the cost of health care for these infants, and another 40 percent is paid by Medicaid. One in nine infants in the U.S. is born preterm. Prematurity is the leading cause of newborn mortality and the second leading cause of infant mortality. Among those who survive, one in five faces health problems that persist for life such as cerebral palsy, intellectual disabilities, chronic lung disease, and deafness. For the past six years preterm birth rates have declined, resulting in 176,000 fewer babies being born preterm and saving more than $9 billion. The March of Dimes believes a key factor behind this continued decline was Congress' passage of the 2006 PREEMIE Act (P.L. 109-450), which brought the first-ever national focus to prematurity prevention and generated a public-private agenda to spur innovative research at the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) and advanced evidence-based interventions to prevent preterm birth. In 2013 Congress passed the PREEMIE Reauthorization Act (P.L. 113-55), which renews our nation's commitment to giving every baby a healthy start. The March of Dimes' FY15 funding requests regarding preterm birth are based on continuing to enhance public and private investment into understanding the causes of preterm birth and promoting known interventions.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

The March of Dimes recommends at least $32 billion for the National Institutes of Health and $1,370 billion for the NICHD in FY 2015. This funding will allow NICHD to sustain its preterm birth-related research through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. This funding would also allow

for NICHD to continue investments in transdisciplinary research to identify the causes of preterm birth, as recommended in the Director's 2012 Scientific Vision for the next decade, the Institute of Medicine 2006 report on preterm birth, and the 2008 Surgeon General's Conference on the Prevention of Preterm Birth. The March of Dimes fully supports NICHD's pursuit of transdisiplinary science, which facilitates the exchange of scientific ideas and leads to novel approaches to understanding complex health issues and their prevention.

Centers for Disease Control and Prevention - Preterm Birth

The mission of the CDC's National Center for Chronic Disease Prevention and Health Promotion's Safe Motherhood Initiative is to promote optimal reproductive and infant health. The March of Dimes recommends funding of $46 million for the Safe Motherhood program and re-instatement of the preterm birth sub-line at $2 million, as reauthorized in the PREEMIE Reauthorization Act, to reflect current preterm birth research within the CDC.

The CDC funds state-based Perinatal Quality Collaboratives, networks of hospitals, health care providers, state health departments, consumer groups, and others that advance evidence-based clinical practices and processes. These networks collect data in real time on health care practices and outcomes and provide immediate feedback for quality improvement. For example, the New York State Obstetrical and Neonatal Quality Collaborative reduced deliveries without indication from 25% in 2010 to 7-8% in 2012. Reducing elective deliveries before 39 weeks gestation is a proven way to lower preterm birth and improve infant outcomes.

Health Resources and Services Administration (HRSA) – Preterm Birth

The March of Dimes recommends the Subcommittee specify $3 million within the Title V Special Projects of Regional and National Significance account be used to support current preterm birth and infant mortality initiatives, as authorized in the PREEMIE Act, and to support

the expansion of its initiatives nationwide. The PREEMIE Reauthorization Act renewed preterm birth-related demonstration projects, which are aimed at improving education, treatment and outcomes for babies born preterm. This funding will support HRSA's Collaborative Improvement & Innovation Network (COIIN) to Reduce Infant Mortality, which assists state agencies focusing on a range of interventions proven to reduce preterm birth and improve maternal and child health.

BIRTH DEFECTS

According to the CDC, an estimated 120,000 infants in the U.S. are born with major structural birth defects each year. Birth defects are the leading cause of infant mortality and the causes of more than 70 percent are unknown. Federal investments are sorely needed to support research to discover the causes of all birth defects and for the development of effective interventions to prevent them or reduce their prevalence.

CDC - National Center on Birth Defects and Developmental Disabilities (NCBDDD)

For FY 2015, the March of Dimes recommends funding of $139 million for NCBDDD. We also request the Subcommittee provide at least $22.3 million to support birth defects research and surveillance and $2.8 million to support folic acid education. Birth defects research and surveillance activities have been severely curtailed due to funding reductions which means a slowed pace to research identifying causes of birth defects and decreased ability to track birth defects and connect families to services. Specifically, two Centers for Birth Defects Research and Prevention have been eliminated. Specific expertise from the previously funded Centers in Texas and Utah (medications used during pregnancy, environmental exposures of concern, maternal infections, and birth defects risk among Hispanics) is no longer contributing to the study and 25% fewer families are participating in CDC birth defects research. Birth defects

surveillance programs funded by NCBDDD have gone from 28 in 2004 to 14 in 2013, with a 40% (800,000) reduction in the number of live births monitored by states.

NEWBORN SCREENING

Newborn screening is a vital public health activity designed to identify genetic, metabolic, hormonal and functional disorders in newborns. Screening detects conditions in newborns that, if left untreated, can cause disability, developmental delays, intellectual disabilities, serious illnesses or even death. If diagnosed early, many of these disorders can be managed successfully. The March of Dimes urges the Subcommittee to provide $18 million for HRSA's heritable disorders program, which plays a critical role in assisting states in the adoption of additional screenings, enhancing provider and consumer education, and ensuring coordinated follow-up care. Also funded by this program is the work of the Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel (RUSP) to ensure that every infant is screened for conditions having a known treatment. The RUSP has helped bring about comprehensive newborn screening in every state. In 2007, only 10 states and DC required infants to be screened for the recommended disorders; today, 42 states and DC require screening of at least 29 of the 31 treatable conditions.

CLOSING

The Foundation's volunteers and staff in every state, the District of Columbia and Puerto Rico look forward to working with Members of this Subcommittee to secure the resources needed to improve the health of the nation's mothers, infants and children.

To the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee Members:

I am Ronald Johnson, Vice President of Policy and Advocacy at AIDS United writing on behalf of the 32 organizational members of our Public Policy Committee and our over 90 programmatic directly funded organizational grantees that are among the leading AIDS Service Organizations across the nation. AIDS United is a national organization that seeks to end the AIDS epidemic in the United States by combining private-sector fundraising, philanthropy, coalition building, public policy expertise, and advocacy, and working with a network of passionate local and state partners to respond effectively and efficiently to the HIV/AIDS epidemic in the communities most impacted by the epidemic. It is AIDS United's request that you fund the Department of Health and Human Services domestic HIV programs at the level of $7.361 billion in Fiscal Year (FY) 2015. This request includes an increase of $931 million over FY 2014 throughout the detailed request listed below.

AIDS United understands the budgetary environment that the country is wrestling with right now is austere. However, we know that investment in HIV prevention and retention in HIV care are critical in lowering the number of new infections in the domestic HIV epidemic. As competing budget priorities are weighed, please keep in mind that HIV is treatable and is 100% preventable and that we have the means to end the AIDS epidemic. The requested increased funding for the domestic HIV/AIDS portfolio in Labor/HHS for FY 2015 will help reach the goals of the National HIV/AIDS Strategy (NHAS). AIDS United looks forward to working with you on the FY 2015 budget.

The Ryan White Program

Early and reliable access to HIV care and treatment is cost effective and helps patients with HIV live healthy and productive lives. The needs of the Ryan White Program (RWP)

continue to grow. Even with the beginning of the implementation of the Affordable Care Act (ACA) and the integration with the RWP there will still be many needs unmet. In order to improve the HIV care continuum and increase progress toward an AIDS-free generation, continued, robust funding for all parts of the Ryan White Program in FY2015 will be necessary.

It will take some time to assess the impact of the ACA on the Ryan White Program. In the meantime, **we urge you to fund the Ryan White Program at a total of $2.44 billion in FY2015, an increase of $123 million over FY2014, distributed in the following manner: Part A: $687 million, Part B (Care): $428 million, Part B (ADAP): $943 million, Part C: $225 million, Part D: $85 million, Part F/AETC: $35 million, Part F/ Dental $15 million, Part F/SPNS: $25 million.**

AIDS United disagrees with the President's budget request to consolidate Part D with Part C. We believe such a major change should only be considered as part of a larger reauthorization process and after key data questions about the value of consolidation are answered.

HIV Prevention

CDC HIV Prevention and Surveillance

According to the Centers for Disease Control and Prevention (CDC), there are an estimated 50,000 new infections annually and about 1 in 6 people living with HIV do not know they have the virus. Gay, bisexual, and other men who have sex with men (MSM) account for 66 percent of all new HIV infections. Between 2008 and 2010, infections among MSM increased by 12 percent, and among MSM aged 13-24 years by 22 percent. Black and Latino MSM, and especially those who are young continue to be disproportionately affected. While we are making progress in decreasing new infections among women, black women accounted for 64 percent of

women infected in 2010. Black and Hispanic women ages 13-24 accounted for 82 percent of young women living with HIV in 2010 even though together they represent only about 30 percent of women these ages.

Investing in HIV prevention today translates into less spending in the future on care and treatment. Increased investments are critical to carry out increased HIV testing programs, targeted interventions, public education campaigns, and HIV surveillance activities.

For FY2015, we request an increase of $55 million over FY2014 for a total of $812.7 million for the CDC Division of HIV prevention and surveillance activities.

Division of Adolescent and School Health (DASH)

One-third of all new HIV infections are among young people under the age of 29, the largest share of any age group. DASH is the only federally funded adolescent health program in our nation's schools, helping education agencies provide school districts and individual schools with the tools to implement high-quality, effective, and sustainable programs to reduce HIV and other STD infections in adolescents. Increased funding would help expand this vital infrastructure beyond the currently funded 36 state or local education agencies.

We request that the CDC Division of Adolescent and School Health receive a total of $47 million, an increase of $16 million over FY14 final funding. This request includes $3 million in evaluation transfer funds.

CDC STD Prevention

Given the strong link between HIV and other STDs, including high rates of co-infection among certain populations, an increased investment in STD programs is an essential component of HIV prevention. Investments in STD prevention and treatment further the National HIV/AIDS Strategy's goal of reducing new HIV infections.

We request an increase of $54 million for a total of $211 million for the CDC's Division of STD Prevention in FY2015.

CDC Viral Hepatitis Prevention

CDC estimates that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the U.S., and as many as 75 percent are not aware of their infection. In 2010 alone, 35,000 Americans were newly infected with HBV and 17,000 with HCV. It is estimated that 10 percent of people living with HIV are co-infected with hepatitis B and 25 percent are co-infected with hepatitis C.

We request an increase of $16 million above the FY2014 level, for a total of $48 million for the CDC's Division of Viral Hepatitis.

Access to Sterile Syringes

About 1 of 12 new infections (8.6 percent) of HIV in 2011 was related to injection drug use, a 28 percent decrease from 2008. One factor leading to this reduction has been syringe exchange programs. Numerous studies have shown syringe exchange programs can be an evidence-based and cost-effective means to lower HIV and hepatitis infections, reduce the use of illegal drugs and help connect people to medical treatment, including substance abuse treatment. In a May 2012 letter, the President's Advisory Council on HIV/AIDS also supported ending the federal ban on syringe exchange and noted that doing so is supported by public health, HIV/AIDS, viral hepatitis and harm reduction communities as well.

We urge you to add language to end the ban on the use of federal funds for syringe exchange programs and to maintain language that allows the use of local funds for syringe exchange programs in the District of Columbia.

Abstinence-only

We request that you eliminate the funding for failed abstinence-only-until-marriage programs.

HIV/AIDS Research at the National Institutes of Health (NIH)

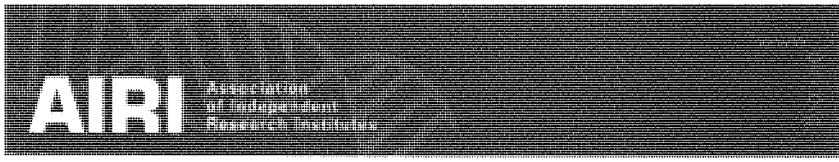
Research continues until better, more effective and affordable prevention and treatment regimens—and eventually a cure—are developed and universally available. For the US to maintain its position as the global leader in HIV/AIDS research for the 33 million people globally living with HIV, of whom 1.1 million are Americans, we must invest adequate resources in the NIH. NIH AIDS research has produced startling advances, including the HPTN 052 study demonstrating treatment as prevention that was named Breakthrough of the Year by *Science* magazine, improved treatment therapies and proof of concept for an HIV vaccine, continued AIDS research funding is essential.

In line with the Trans-NIH AIDS Research By-Pass Budget Estimate for FY2013, please include $3.6 billion for HIV research at the NIH, an increase of $610 million over FY2014.

Minority HIV/AIDS Initiative

HIV/AIDS continues to impact communities of color at an alarming rate. According to the CDC, African Americans, more than any other racial/ethnic group, continue to bear the greatest burden of HIV in the U.S. While black people represent approximately 12 percent of the total population, they accounted for 44 percent of all new HIV infections in 2010. Hispanics represent approximately 16 percent of the total population, but accounted for 21 percent of all new HIV infections. In the Asian Pacific Islander, and Native American communities the numbers of HIV infection are just as startling.

We request that the MAI be funded at $610 million in FY2015. *We note that most of these funds are contained within the budgets of the programs described above.*



Written Statement for the Record Submitted by
Association of Independent Research Institutes
for the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

Fiscal Year 2015 Funding for the
National Institutes of Health, Department of Health and Human Services
March 28, 2014

The Association of Independent Research Institutes (AIRI) thanks the Subcommittee for its long-standing and bipartisan leadership in support of the National Institutes of Health (NIH). We continue to believe that science and innovation are essential if we are to continue to improve our nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy. The Consolidated Appropriations Act of 2014 included a welcome and much needed increase for NIH. However, this increase did not give back all of the funds cut by sequestration in FY 2013 nor did it restore the purchasing power NIH has lost over the past decade. We hope FY 2014 represents a first step toward restoring our nation's preeminence in medical research. AIRI recommends that NIH receive at least **$32 billion in FY 2015** as the next step toward a multi-year increase in our nation's investment in medical research.

AIRI is a national organization of more than 80 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 they receive about ten percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is a unique and highly-productive relationship, leveraging the full strength of our nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients. Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every state.

The federal government has an irreplaceable role in supporting medical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge research necessary to yield new innovations and technologies of

the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more. Unfortunately, continued erosion of the national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

The NIH 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 that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. AIRI institutes are specifically focused on pursuing knowledge around the biology and behavior of living systems and applying that knowledge to improve human health and reduce the burdens of illness and disability. Additionally, AIRI member institutes have championed (and very frequently are called upon to lead) technologies and research centers to collaborate on biological research for all diseases. Using shared resources – specifically, advanced technology platforms or "cores," – as well as genomics, next-generation sequencing, electron and light microscopy, high-throughput compound screening, bioinformatics, imaging, and other technologies, AIRI researchers advance therapeutics development and drug discovery.

AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall. In addition to concerns over

funding, AIRI member institutes oppose legislative provisions – such as directives to reduce the salary limit for extramural researchers – which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Such prescriptive policies hinder AIRI members' research missions and their ability to recruit and retain talented researchers. AIRI also does not support legislative language limiting the flexibility of NIH to determine how to most effectively manage its resources while funding the best scientific ideas.

AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

AIRI members are located in 25 states, including many smaller or less-populated states that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

The biomedical research community depends upon a knowledgeable, skilled, and diverse

workforce to address current and future critical health research questions. While the primary function of AIRI member institutions is research, most are highly involved in training the next generation of biomedical researchers, ensuring that a pipeline of promising scientists is prepared to make significant and potentially transformative discoveries in a variety of areas. AIRI supports policies that promote the ability of the United States to maintain a competitive edge in biomedical science. The NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health.

AIRI thanks the Subcommittee for its important work dedicated to ensuring the health of the nation, and we appreciate this opportunity to urge the Subcommittee to **provide $32 billion for NIH in the FY 2015 appropriations bill**. AIRI also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander valuable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic future.

FASEB
Federation of American Societies for Experimental Biology

Representing Over 115,000 Researchers

301.634.7000 9650 Rockville Pike
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March 28, 2014
Contact: Jennifer Zeitzer
Director of Legislative Relations
Federation of American Societies for Experimental Biology

Testimony of the

Federation of American Societies for Experimental Biology

On

FY 2015 Appropriations for the National Institutes of Health

Submitted to the

House Committee on Appropriations

Subcommittee on Labor, Health and Human Services, Educations, and Related Agencies

Representative Jack Kingston, Chairman

Representative Rosa DeLauro, Ranking Member

The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a minimum of $32 billion in fiscal year (FY) 2015 for the National Institutes of Health (NIH) within the Department of Health and Human Services. Increasing the NIH budget to $32 billion would support vital initiatives to train the next generation of scientists, and fund at least 600 additional competing research grants.

FASEB, a federation of 26 scientific societies, represents more than 115,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. Our mission is to advance health and welfare by promoting progress and education in

biological and biomedical sciences.

NIH has produced an outstanding legacy of discoveries that have generated new knowledge, improved health, and saved lives. Many of these advances arose from investigations designed to explain basic molecular, cellular, and biological mechanisms. In addition, research supported by NIH led to innovative technologies and created entirely new global industries resulting in economic growth and new, high-tech jobs.

As a result of our prior investment in NIH, we have reduced the death toll of many diseases and reduced the disability and suffering from many others. For example, U.S. death rates from heart disease and stroke have decreased by more than 60 percent in the last 50 years, the rate of acute hepatitis B has been reduced by 80 percent since the 1980's, and the proportion of older people with chronic disabilities has dropped by one-third over the last quarter century. Research funded by NIH helped develop new treatments that have significantly reduced the transmission of human immunodeficiency virus from mother to child and provided insights into traumatic brain injury. In addition, with the completion of the Human Genome Project and subsequent technological advances in rapidly sequencing DNA, scientists have been able to identify genes that are responsible for more than half of the 7,000 rare diseases known to affect humans and evaluate the genetic composition of various cancers with the hopes of pinpointing the most effective therapy for each individual patient.

NIH-supported research is continuing to produce the insights that are needed for tomorrow's improvements in health and clinical care. Recent discoveries include:

- *Advances in Treating Melanoma*: Years of basic research supported by NIH have provided insights into biological changes that occur in the development of cancer,

including the observation that a protein called b-Raf appears in a mutated form in more than 50 percent of melanomas, the most aggressive form of skin cancer. Studies showing that this protein plays a critical role in melanoma led pharmaceutical companies to develop drugs to inhibit mutant b-Raf. These drugs can s improve quality of life and prolong survival in the majority of patients with advanced melanoma who harbor b-Raf mutations. Since most of these patients eventually relapse and die from their disease, studies are underway to understand why melanomas become resistant to treatment. It is hoped that this will lead to new treatments that can overcome or bypass resistance, with the goal of achieving long-term remissions and cures.

- *Developing Structure-Based Vaccines:* Respiratory syncytial virus (RSV) is responsible for nearly seven percent of deaths of infants under 12 months of age. It also causes death and disability in the elderly. NIH-funded research has illuminated many aspects of RSV infection and pathogenesis, yet an effective vaccine has remained elusive. Recently, investigators made a breakthrough by determining the three-dimensional structure of an RSV protein required for cell entry. This structural information was then used to design a stabilized vaccine antigen that elicited high titers of protective antibodies in mice and non-human primates. In the next few years, this promising vaccine candidate will be tested in clinical trials, and it is hoped that this structure-based approach to vaccine design will be successful for other viruses, such as HIV-1.

- *Testing New Anti-Inflammatory Drugs*: In the 1990's, NIH supported a few academic researchers to study molecules called glycans for their function in inflammation, the process the body uses to fight infection. In 2013, these studies came to fruition with the

first tests of a new, glycan-based anti-inflammatory drug. In an initial test to fight inflammation during the painful crises that occur in sickle cell disease, both children and adult patients who got this treatment had shorter disease crises, spent less time in the hospital, and needed fewer narcotics for pain relief. This new drug that will benefit tens of thousands of people in the U.S. each year could never have been developed without NIH's investment in exploratory basic research.

- *Harnessing the Immune System to Fight Cancer*: *Science* magazine named cancer immunotherapy–using the immune system to attack tumors– the 2013 Breakthrough of the Year. The early work that led to the development of immunotherapy was made possible by NIH-funded research on many basic biological processes, including the biology of T cells, a family of cells that are critical to the immune system. Researchers discovered that when a certain receptor on the outside of T cells is activated, cells cannot mount an effective immune response. They then reasoned that if an antibody blocked the activation of this receptor, T cells could be induced to attack tumor cells. Ongoing clinical trials testing antibody immunotherapies in individuals found that tumors shrunk by almost 50 percent in 31 percent of those with melanoma and 29 percent in those with kidney cancer.

Further Progress Depends on Sustained Investment

Research supported by NIH advances our understanding of the nature of living systems and enables us to apply that knowledge to the improvement of human health. In a recent op-ed in *The Washington Post*, NIH Director Francis S. Collins, MD, PhD, wrote, "Biomedical research is at a critical juncture –a moment of exceptional opportunities that demand exceptional attention if

their promise is to be fully realized."[1] But without continued support for basic biomedical research, Dr. Collins fears that we will miss out on new discoveries that will give us the next generation of cures and therapies for such conditions as Parkinson's disease and Alzheimer's disease, as well as a universal vaccine to protect adults and children against all flu strains without needing an annual shot.

While the opportunities to increase our understanding of diseases and develop new therapies are unprecedented, a decade of flat-funding—followed by $1.55 billion in sequestration cuts in FY 2013—have taken a significant toll on NIH's ability to support research. In constant dollars (adjusted for inflation), the FY 2013 budget for NIH was the lowest in thirteen years. The number of competing R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, awarded each year fell by 34 percent between 2003 and 2013. The current situation is decimating the ranks of our scientific workforce, causing productive scientists to seek alternative careers and discouraging talented trainees from pursuing jobs in academic research. It surrenders our future leadership in medical research.

As a first step toward a multi-year program of sustainable growth, FASEB recommends a minimum of $32 billion for NIH in FY 2015. Thank you for the opportunity to offer FASEB's FY 2015 funding recommendation for NIH.

[1] Collins, F. (2013, December 24). Investing in the Nation's Health at NIH. *Washington Post.*

TESTIMONY ON BEHALF OF THE FRIENDS OF NIAAA
SUBMITTED BY CARLO DiCLEMENTE, CHAIR

On behalf of the newly re-launched Friends of NIAAA, I urge the Labor, Health and Human Services, Education Appropriations Subcommittee to support at least $32 billion for the National Institutes of Health (NIH), including $478 million for NIAAA for FY2015. This funding recommendation represents the minimum investment necessary to avoid further loss of promising research and at the same time allows the NIH's budget to keep pace with biomedical inflation. Our coalition includes organizations representing scientists, physicians, health care providers, patients and families all pleased to support the work of NIAAA.

Since its establishment in 1970, NIAAA has achieved great success in meeting the objectives of its broad research mission. With sufficient resources, NIAAA could build upon the promising initiatives described in this testimony and produce new insights into why and how people drink; why some people develop alcohol use disorders; how alcohol affects the development of young brains and bodies; why there is end organ damage in some people and not others; and how prevention, treatment and recovery programs can be improved. Scientific breakthroughs supported by NIAAA will reduce alcohol-related problems, and the Institute will highlight and disseminate its findings to help develop science-based policies around alcohol use and abuse.

Critical research is being conducted at NIAAA in many areas, including those highlighted below:

Alcohol and Pregnancy: Despite the known effects of alcohol use in pregnancy, 1 in 5 women will drink alcohol during their first trimester, 1 in 14 women will drink during their second trimester, and 1 in 20 will drink during their third trimester. This situation results in 40,000

babies born each year with fetal alcohol spectrum disorder (FASD), making it the number one cause of preventable birth defects. And FASD is a lifespan issue – FASD children become FASD adults. It is imperative that we better understand the link between maternal alcohol use and FASD..

The resources provided by the NIAAA, including the handout for patients: Re-thinking Drinking and the print and video materials for providers has become a standard of care for our providers. NIAAA staff has been a guiding force in the development clinical of intervention methods.

Impact on Families: NIAAA informs public health by supporting research on children, families, and alcohol abuse. Research on children and families is especially important as, according to a 2012 study, more than 10% of U.S. children live with a parent who has alcohol problems. Research also tells us that alcohol abuse can start young: In 2009, 10.4 million young people ages 12 to 20 reported that they drank alcohol beyond "just a few sips" in the past month. NIAAA-supported researchers have investigated a range of topics that help us better understand how to support children and families facing issues related to alcohol use. For example, studies have looked at:

- Behavior problems in the children of alcoholic parents;
- Friendship characteristics and problem behaviors among adolescents; and
- Behavioral control and resiliency (the degree to which people can adapt flexibly to express or contain impulses and behaviors) in the onset of alcohol and illicit drug use among adolescents.

Moreover, given the scope and complexity of the problems associated with underage drinking--including date rape, assault, unintentional injury and even death--it is critical that one of

[Type text]

NIAAA's major research initiatives is the Underage Drinking Research Initiative, an interdisciplinary program that looks at the environment, genetics, biology, and behavior. Through this initiative, NIAAA has not only funded important research but has also created valuable tools for parents, pediatricians, and colleges.

Liver and End Organ Damage Research: No less than 30,000 Americans die annually from alcohol-related liver disease. Research guided by NIAAA on alcohol metabolism and its consequences have been the foundation for discoveries in obesity and metabolic syndrome research, two fields critical to public health. NIAAA is the only NIH Institute that supports research on the combined effects of alcohol and other liver diseases like hepatitis B and C viral infections and HIV. NIAAA funded research has been critical in examining the linkage between the gut, liver and brain as well as addressing end-organ damage caused by alcohol.

Public Health Practices: The NIAAA might exist to guide research on the impact of alcoholism, but it is the transformation of this research into health practices that most directly illustrates the value of this institute. Health professionals across the spectrum, from physicians to nurses to addiction counselors to psychologists to social workers, rely on NIAAA research to design treatment and prevention protocols that are efficient, effective, and modern. These professionals rely on research to design evidence based practices, combining what they have learned about the psychology, biology, and sociology of alcohol abuse at all age levels and across all demographics. Treatment for alcoholism is not a "one size fits all" proposition, and we must continue to support NIAAA research if we are to see improved treatment outcomes. In a time when so much emphasis is being placed on access to quality health care, we cannot ignore the role research plays in shaping such care. Alcoholism is one of the deadliest, costliest diseases in America. As Americans gain greater access to care, research must keep pace.

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Furthermore, strong federal support of NIAAA is needed in order to ensure that the work of the Institute is ultimately translated into every day practice. In particular, federal funds are needed in order to maintain a strong partnership between NIAAA and State substance abuse agencies – the entities in each State responsible for planning and implementing the substance abuse prevention, treatment and recovery system. NIAAA's partnership with these leaders is critical in order to ensure research findings are relevant and implementable by state substance abuse systems. Further, resources are needed to promote "Practice-to-Research" initiatives – allowing for the rigorous study of "promising practices" that in turn may potentially be replicated elsewhere in the country.

These research efforts have made significant contributions to the well-being of all Americans, but there is still much to discover. We urge you to support NIAAA at funding levels that meet current needs for addressing these and other critical health issues addressed by NIAAA research. Thank you for your consideration and we look forward to working with you on these critical issues.

Testimony of the Alzheimer's Association
Fiscal Year 2015 Appropriations for Alzheimer's-related Activities
at the U.S. 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

March 28, 2014

The Alzheimer's Association appreciates the opportunity to comment on the Fiscal Year (FY) 2015 appropriations for Alzheimer's disease research, education, outreach and support at the U.S. Department of Health and Human Services.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. As the world's largest nonprofit funder of Alzheimer's research, the Association is committed to accelerating progress of new treatments, preventions and, ultimately, a cure. Through our funded projects and partnerships, we have been part of every major research advancement over the past 30 years. Likewise, the Association works to enhance care and provide support for all those affected by Alzheimer's and reaches millions of people affected by Alzheimer's and their caregivers.

Alzheimer's Impact on the American People and the Economy

In addition to the human suffering caused by the disease, Alzheimer's is creating an enormous strain on the health care system, families and the federal budget. Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking and other brain functions. Ultimately, Alzheimer's is fatal. Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. Over five million Americans are living with Alzheimer's, with 200,000 under the age of 65.

A federal commitment can lower costs and improve health outcomes for people living with Alzheimer's today and in the future. By making Alzheimer's a national priority, we can create the same successes that we have been able to achieve in other diseases that have been prioritized by the federal government. Leadership from the federal government has helped to lower the number of deaths from other major diseases like heart disease, HIV/AIDS, many cancers, heart disease and stroke. While those deaths have declined, deaths from Alzheimer's have increased 68 percent between 2000 and 2010.

Alzheimer's is the most expensive disease in America. In fact, an NIH-funded study in the *New England Journal of Medicine*

confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates. If nothing is done, as many as 16 million Americans will have Alzheimer's disease by 2050 and costs will exceed $1.2 trillion (not adjusted for inflation), creating an enormous strain on the healthcare system, families and the federal budget. The expense involved in caring for those with Alzheimer's is not just a long-term problem. As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

Due to these projected increases, the graying of America threatens the bankrupting of America. Caring for people with Alzheimer's will cost all payers - Medicare, Medicaid, individuals, private insurance and HMOs -- $20 trillion over the next 40 years, enough to pay off the national debt and still send a $10,000 check to every man, woman and child in America. In 2014, America will spend an estimated $214 billion in direct costs for those with Alzheimer's, including $150 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 19 times higher.

A primary reason for these costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidity that complicate the management of the condition(s) and increase costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes. Nearly 30 percent of people with Alzheimer's or another dementia who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without Alzheimer's or dementia. Alzheimer's disease is also extremely prevalent in nursing homes, where 64 percent of Medicare residents live with the disease.

With Alzheimer's, it is not just those with the disease who suffer - it is also their caregivers and families. In 2013, 15.5 million family members and friends provided unpaid care valued at over $220 billion. Caring for a person with Alzheimer's takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves. More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with one-third reporting symptoms of depression. Caregiving may also have a negative impact on health, employment, income and family finances. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had $9.3 billion in additional health costs in 2013.

Changing the Trajectory of Alzheimer's

Until recently, there was no federal government strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (P.L. 111-375) passed unanimously, requiring the creation of an annually-

updated strategic National Alzheimer's Plan (Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. The Plan is required to include an evaluation of all federally-funded efforts in Alzheimer's research, care and services -- along with their outcomes. In addition, the Plan must outline priority actions to reduce the financial impact of Alzheimer's on federal programs and on families; improve health outcomes for all Americans living with Alzheimer's; and improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based Alzheimer's programs for individuals with Alzheimer's and their caregivers. NAPA will allow Congress to assess whether the nation is meeting the challenges of this disease for families, communities and the economy. Through its annual review process, NAPA has enabled, for the first time, Congress and the American people to answer this simple question: *Did we make satisfactory progress this past year in the fight against Alzheimer's?*

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services, has developed the first-ever *National Plan to Address Alzheimer's Disease* in May of 2012 and subsequently released the *2013 Update to the National Plan to Address Alzheimer's Disease* this past June. The Advisory Council, composed of both federal members and expert non-federal members, is an integral part of the planning process as it advises the Secretary in developing and evaluating the annual Plan, makes recommendations to the Secretary and Congress, and assists in coordinating the work of federal agencies involved in Alzheimer's research, care, and services.

Having a plan with measurable outcomes is important. But unless there are resources to implement the plan and the will to abide by it, we cannot hope to make adequate progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. Understanding this and following the recommendation of scientists at NIH, Congress passed the *Consolidated Appropriations Act of 2014* (P.L. 113-76) which included a $100 million increase for Alzheimer's research. These funds are a critically needed down payment for needed research and services for Alzheimer's patients and their families.

A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in health care costs. Specifically, if a treatment became available in 2015 that delayed onset of Alzheimer's for five years (a treatment similar to anti-cholesterol drugs), savings would be seen almost immediately, with Medicare and Medicaid spending reduced by $42 billion in 2020.

Today, despite the federal investment in Alzheimer's research, we are only just beginning to understand what causes the disease. Americans are growing increasingly concerned that we still lack effective treatments that will slow, stop, or cure the disease, and that the pace of progress in developing breakthrough discoveries is much too slow to significantly impact on this growing crisis. For every $26,500 Medicare and Medicaid spends caring for individuals with Alzheimer's, the National Institutes of Health (NIH) spends

only $100 on Alzheimer's research. Scientists fundamentally believe that we have the ideas, the technology and the will to develop new Alzheimer's interventions, but that progress depends on a prioritized scientific agenda and on the resources necessary to carry out the scientific strategy for both discovery and translation for therapeutic development.

For too many individuals with Alzheimer's and their families, the system has failed them, and today we are unnecessarily losing the battle against this devastating disease. Despite the fact that an early and documented formal diagnosis allows individuals to participate in their own care planning, manage other chronic conditions, participate in clinical trials, and ultimately alleviate the burden on themselves and their loved ones, as many as half of the more than five million Americans with Alzheimer's have never received a formal diagnosis. Unless we create an effective, dementia-capable system that finds new solutions to providing high quality care, provides community support services and programs, and addresses Alzheimer's health disparities, Alzheimer's will overwhelm the health care system in the coming years. For example, people with Alzheimer's and other dementias have more than three times as many hospital stays as other older people. Furthermore, one out of seven individuals with Alzheimer's or another dementia lives alone and up to half do not have an identifiable caregiver. These individuals are more likely to need emergency medical services because of self-neglect or injury, and are found to be placed into nursing homes earlier, on average, than others with dementia. Ultimately, supporting individuals with Alzheimer's disease and their families and caregivers requires giving them the tools they need to plan for the future and ensuring the best quality of life for individuals and families impacted by the disease. It is vital that we make the investments in Alzheimer's that will fulfill the goals of the National Alzheimer's Plan. **The Alzheimer's Association urges Congress to support an additional $200 million for research activities and priorities included in the National Alzheimer's Plan required under P.L. 111-375.**

Additional Alzheimer's programs

National Alzheimer's Call Center: The National Alzheimer's Call Center, funded by the AoA, provides 24/7, year-round telephone support, crisis counseling, care consultation, and information and referral services in 140 languages for persons with Alzheimer's, their family members and informal caregivers. Trained professional staff and master's-level mental health professionals are available at all times. In the 12 month period ending July 31, 2013, the Call Center handled over 300,000 calls through its national and local partners, and its online message board received over 40,000 visits a month. Additionally, the Association provides a two-to-one match on the federal dollars received for the call center. **The Alzheimer's Association urges Congress to support $1.3 million for the National Alzheimer's Call Center.**

Healthy Brain Initiative (HBI): The Centers for Disease Control and Prevention's (CDC) HBI program works to educate the public, the public health community and health professionals about Alzheimer's as a public health issue. Although there are currently no treatments to delay or stop the deterioration of brain cells caused by Alzheimer's, evidence suggests that preventing or controlling cardiovascular risk factors may benefit brain health. In light of the dramatic aging of the population, scientific advancements in risk behaviors, and the growing awareness of the significant health, social and economic burdens associated with cognitive decline, the federal commitment to a public health response to this challenge is imperative. The FY 2014 omnibus funding bill increased funding for HBI by $1.5 million in order to bolster caregiver surveillance. **The Alzheimer's Association urges Congress to support $3.3 million for the Healthy Brain Initiative.**

Alzheimer's Disease Supportive Services Program (ADSSP): The ADSSP at the AoA supports family caregivers who provide countless hours of unpaid care, thereby enabling their family members with Alzheimer's and dementia to continue living in the community. The program develops coordinated, responsive and innovative community-based support service systems for individuals and families affected by Alzheimer's. **The Alzheimer's Association urges Congress to support $13.4 million for the Alzheimer's Disease Supportive Services Program.**

Conclusion

The Association appreciates the steadfast support of the Subcommittee and its priority setting activities. We look forward to continuing to work with Congress in order to address the Alzheimer's crisis. We ask Congress to address Alzheimer's with the same bipartisan collaboration demonstrated in the passage of the National Alzheimer's Project Act (P.L. 111-375) and with a commitment equal to the scale of the crisis.

John Madigan
Vice President of Public Policy
American Foundation for Suicide Prevention

March 25, 2014

The Honorable Jack Kingston
Chairman
Appropriations Subcommittee on Labor, Health and Human Services and Education
U.S. House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Appropriations Subcommittee on Labor, Health and Human Services and Education
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Kingston and Ranking Member DeLauro:

As you begin work on the FY 2015 Labor, Health and Human Services, and Education Appropriations bill, the American Foundation for Suicide Prevention (AFSP) respectfully urges you to support investments in public health research by including $40 million for the National Institute of Mental Health to conduct suicide prevention and brain research including studies designed to reduce the risk of self-harm, suicide, and interpersonal violence; $25 million for the National Violent Death Reporting System (NVRDS) at the Centers for Disease Control and Prevention (CDC); $60.15 million for suicide prevention programs under the Garrett Lee Smith Memorial Act (GLSMA) through the Substance Abuse Mental Health Services Administration (SAMHSA); and $20 million for the Mental Health First Aid Program (MHFA).

$40 Million in Funding for Suicide Prevention Research

Suicide, already the 10th leading cause of death overall in the U.S., the 3rd leading cause of death among 15-24 year olds, and the 2nd leading cause of death among 24-34 year olds; continues to

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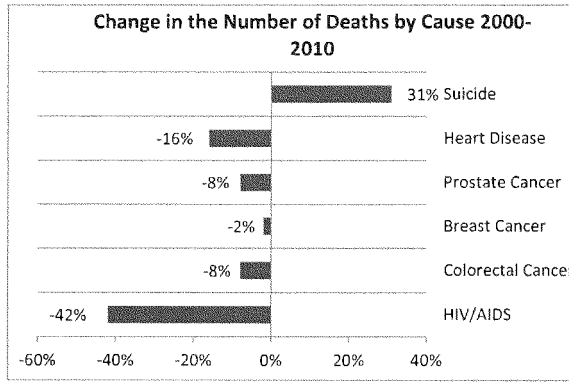
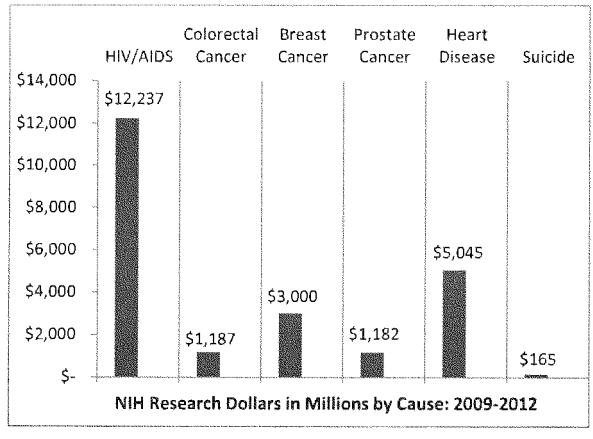
take more and more lives each year. In 2010 (latest available data), suicide took the lives of more than 38,000 Americans, up 31% from 2000.

The graphs to below compare the change in number of deaths by cause (2000-2010) to the total amount of research dollars spent by the National Institutes of Health (NIH) on those causes from FY 2009-FY 2012:

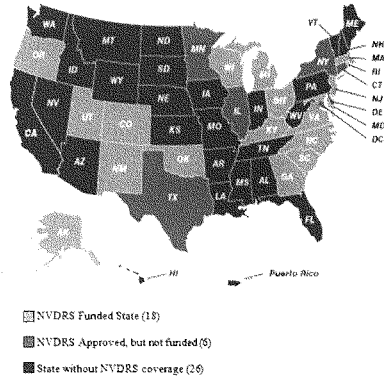




AFSP supports at a minimum a $40 million investment in suicide prevention research as recommended by Representative Ron Barber in H.R. 4075 (the Suicide Prevention Research Innovation Act or SPRINT Act) so we can obtain similar reductions in suicide mortality that have resulted from strategic investments in other major public health concerns.

Full Funding of $25 Million for the National Violent Death Reporting System (NVDRS)

The NVDRS collects in-depth information on the details of and circumstances surrounding each suicide, which goes beyond the basic information collected through the CDC's National Vital Statistics Reports/Fatal Injury Report and implementing the NVDRS nationwide is essential to developing, informing and evaluating suicide prevention programs.



Currently, the National Violent Death Reporting System collects surveillance data in only 18 states (Alaska, Colorado, Georgia, Kentucky, Maryland, Massachusetts, Michigan, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Utah, Virginia and Wisconsin). The data collected helps inform policy makers on trends and characteristics of violent deaths within specific communities so they can design appropriate prevention measures and evaluate ongoing efforts to curb violence.

Included in the FY 2014 omnibus appropriations bill was an additional $7.7 million (bringing the program total to $11.2 million) in funding to expand the program; however, AFSP requests the full $25 million be provided so the CDC would have the resources to scale up this effort to include all 50 states. Today, there exists no other data surveillance system that offers this benefit for such a modest investment. No other data collection or centralization effort carries the inherent value associated with NVDRS and, in fact, no other effort has the ability to directly inform and impact state and federal suicide prevention activities.

Funding of $60.15 Million for GLSMA Suicide Prevention Programs

Since its creation in 2004, GLSMA has provided resources to communities and college campuses all across the country, and supported needed technical assistance to develop and disseminate effective strategies and promising practices related to youth suicide prevention. To date, the GLSMA has supported youth suicide prevention grants in 49 states, the District of Columbia and Guam, 48 Tribes or Tribal organizations, and 138 institutions of higher education.

AFSP requests that the Committee approve $60.15 million for GLSMA programs in FY 2015 to ensure a continuation of these critically important youth and college suicide prevention programs.

Funding of $20 Million for Mental Health First Aid (MHFA)

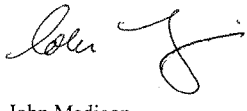
Sometimes, first aid isn't a bandage, or CPR, or the Heimlich, or calling 911. Sometimes, first aid is you. While many Americans know how to administer first aid and seek medical help should they come across a person having a heart attack, few are trained to provide similar help to someone experiencing a mental health or substance abuse crisis.

Mental Health First Aid is a public education program that helps people identify, understand, and respond to signs of mental illnesses and substance abuse. The course teaches participants a 5-step action plan to reach out to a person in crisis and connect them with professional, peer, or other help.

AFSP requests that $20 million be approved for MHFA training programs around the country that would train participants in recognizing the symptoms of common mental illnesses and addiction disorders, de-escalating crisis situations safely, and initiating timely referral to mental health and substance abuse resources available in the community.

Thank you for your time and consideration of these requests by the American Foundation for Suicide Prevention. Should you have any questions I can be reached at (202) 449-3600 ext. 103 or at jmadigan@afsp.org.

Sincerely,



John Madigan
Vice President of Public Policy

AMERICAN SOCIETY OF HEMATOLOGY
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American Society of Hematology Statement to the House Appropriations Subcommittee on Labor, HHS, Education, and Related Agencies in Support of Fiscal Year 2015 Funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC)
March 28, 2014

The American Society of Hematology (ASH) thanks the Subcommittee for the opportunity to submit written testimony on the fiscal year (FY) 2015 Departments of Labor, Health and Human Services, and Education Appropriations bill.

ASH represents more than 15,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, gene- and immunotherapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

Funding for Hematology Research: An Investment in the Nation's Health

Over the past 60 years, American biomedical research has led the world in probing the nature of human disease. This research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries. This research would not have been possible without support from the National Institutes of Health (NIH).

Funding for hematology research has been an important component of this investment in the nation's health. Most of the research that produced cures and treatments for hematologic diseases has been funded by the NIH. The study of blood and its disorders is a trans-NIH issue involving many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA).

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs.

Additionally, as NIH Director Francis Collins recently noted in his testimony to the Subcommittee, researchers are "aiming to harness the body's own immune system to fight cancer." One such method, known as chimeric antigen receptor (CAR) cell engineering, extracts T cells (naturally occurring immune cells) from the blood of a cancer patients and modifies the cells to produce special proteins on their surface. With these new engineered features, the T cells are injected back into the patient, now primed to seek and destroy cancer cells. Preliminary studies have found that this process may generate responses in as many as two-thirds of cases in which all other treatment options have failed. Further, because the cells are derived from the

patient, there is an inherently lower risk of toxicity because the cells are less likely to attack the host tissue than cells introduced from a foreign body. Promising results in patients with leukemia prompted *Science* magazine to name this its 2013 "Breakthrough of the Year."

Hematology advances also help patients with other types of cancers, heart disease, and stroke. Even modest investments in hematology research have yielded large dividends for other disciplines. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS. Blood thinners effectively treat or prevent blood clots, pulmonary embolism, and strokes. Death rates from heart attacks are reduced by new forms of anticoagulation drugs.

Sequestration Threatens Scientific Momentum

ASH is particularly concerned about the impact of continued cuts on biomedical research supported by the NIH. NIH's ability to continue current research capacity and encourage promising new areas of science is, and will be, significantly limited. At a time when we should be investing more in research to save lives, research funding remains in serious jeopardy. Trials to find new therapies and cures for millions of Americans with blood cancers, bleeding disorders, clotting problems, and genetic diseases are just a few of the important projects that could be delayed unless NIH continues to receive predictable and sustained funding.

Additionally, perhaps one of the greatest concerns is the obstacle these continued cuts will present to the next generation of scientists, who will see training funds slashed and the possibility of sustaining a career in research diminished. The Society is especially concerned about the

number of scientists who have abandoned research careers; continued cuts will exacerbate this exodus, forcing researchers to abandon potentially life-enhancing research.

FY 2015 NIH Funding Request

ASH appreciates the welcome and much needed funding increase for the NIH that Congress provided in the Consolidated Appropriations Act of 2014. However, this increase did not give back all of the funds cut by sequestration in FY 2013 nor did it restore the purchasing power lost over the past decade. ASH supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in our nation's investment in medical research. ASH also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic future.

Centers for Disease Control and Prevention (CDC) Public Health Response for Blood Disorders

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders. Blood disorders – such as sickle cell disease, anemia, blood clots, and hemophilia – are a serious public health problem and affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. Men, women, and children of all backgrounds live with the complications associated with these conditions, many of which are painful and potentially life-threatening.

CDC is uniquely positioned to reduce the public health burden resulting from blood disorders by contributing to a better understanding of these conditions and their complications; ensuring that prevention programs are developed, implemented, and evaluated; ensuring that information is accessible to consumers and health care providers; and encouraging action to improve the quality of life for people living with or affected by these conditions. The Society is concerned that the Division of Blood Disorders was cut by nearly $6 million in the Consolidated Appropriations Act of 2014 and the President's Budget for FY 2015 did not restore this funding. ASH respectfully requests that the Division of Blood Disorders be funded in FY 2015 at $19 million to assure that the programs funded by the Division for Hemophilia, Thalassemia, Sickle Cell Disease, and DVT/PE can be maintained. This funding will allow CDC to improve health outcomes and limit complications to those who are risk or currently have blood disorders, by promoting a comprehensive care model; identifying and evaluating effective prevention strategies; and increasing public and healthcare provider awareness of bleeding and clotting disorders such as such as hemophilia and thrombosis, and hemoglobinopathies, including sickle cell disease and thalassemia.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, at 202-776-0544 or *troades@hematology.org*, if you have any questions or need further information concerning hematology research or ASH's FY 2015 funding request.

Our mission is "to provide optimal care and services to individuals confronting dementia and to their caregivers and families – through member organizations dedicated to improving quality of life."

House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies Written Testimony for the Record by the Honorable Charles J. Fuschillo, Jr., Chief Executive Officer, Alzheimer's Foundation of America

RE: FY 2015 Appropriations for Department of Health and Human Services (HHS) Programs Impacting Americans with Alzheimer's Disease

On behalf of the Alzheimer's Foundation of America (AFA), a national nonprofit organization that unites more than 1,600 member organizations nationwide with the goal of providing optimal care and services to individuals confronting dementia, and to their caregivers and families, we are making the following appropriations requests for programs impacting Alzheimer's disease caregiving services and research in the fiscal year (FY) 2015 budget. These federal programs and support services are vital to providing necessary care supports and promoting best practice tools to family caregivers, and advancing promising clinical research.

Specifically, AFA makes the following appropriations requests for these specific agencies and programs:

National Institutes of Health (NIH):

Adequate investment in scientific research that could lead to new treatments and cures is critical in order to reduce long-term healthcare costs. We appreciated Congress' efforts in the FY 2014 budget which provided an additional $80 million for clinical research into Alzheimer's disease. **AFA urges the Committee to build on this modest increase and provide an additional**

$500 million for Alzheimer's disease research and enhanced investments for caregiving supports and services in FY '15. Additional resources will fund effective pharmaceutical therapies to prevent, cure or slow the progression of Alzheimer's disease, and provide the necessary seed money to implement and facilitate the ambitious and laudable goals of the "National Plan to Address Alzheimer's Disease."

AFA also urges the Committee to include $32 billion in total funding for NIH, as recommended by the Ad Hoc Group for Medical Research and a bi-partisan group of Members of Congress including Reps. McKinley, Davis, Carson and King. Even if funding remains flat, NIH's actual budget will still be effectively cut as spending will not be able to keep pace with biomedical inflation.

- National Institute on Aging (NIA): Since NIA is the primary agency responsible for Alzheimer's disease research, **AFA urges the Committee to include a minimum budget appropriation of $1.7 billion, an increase of $500 million for NIA in FY 2015**.

NIA leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults, whose numbers are projected to rise dramatically in the coming years due to increased life expectancy and the aging of the baby boom generation.

This funding is essential to increase the NIA's baseline to a level consistent with comparable research initiatives conducted under the auspices of NIH, and to support additional research into Alzheimer's disease and related dementias. This is particularly vital, as Alzheimer's disease holds the infamous position of being the only one of the top ten leading causes of death with a rising death rate.

Administration on Community Living (ACL) programs:

AFA would like to single out the following programs within the ACL that are critical to individuals with Alzheimer's disease and their caregivers:

- National Family Caregiver Support Program (NFCSP): NFCSP provides grants to states and territories, based on their share of the population aged 70 and over, to fund a range of supportive services that assist family and informal caregivers in caring for their loved ones at home for as long as possible, thus providing a more person-friendly and cost-effective approach than institutional care. The FY 14 appropriation level of $146 million cannot possibly keep up with the need for respite care as our population ages. **AFA urges that $156 million be appropriated in FY 2015 to support this important program.**

- Lifespan Respite Care Program (LRCP): **AFA urges the Committee to commit $10 million to LRCP in FY 2015.** LRCP provides competitive grants to state agencies working with Aging and Disability Resource Centers and non-profit state respite coalitions and organizations to make quality respite care available and accessible to family caregivers regardless of age or disability by establishing State Lifespan Respite Systems.

- Alzheimer's Disease Demonstration Grants (ADDG): Existing resources for the Alzheimer's population and their caregivers are already tapped out, at a time when demand is continuing to rise in line with the skyrocketing incidence of this disease. **AFA supports funding of $9 million for this program** which fosters the development of innovative models of care for persons with Alzheimer's disease and their caregivers and is designed to improve responsiveness of the

home and community based care system to persons with dementia including underserved minority, rural and low-income persons.

- Alzheimer's Disease Initiative (ADI): **AFA supports the President's FY '15 budget request of $12 million for this program** that for services such as support for caregivers in the community, improving health care provider training, and raising public awareness. Research shows that education, counseling and other support for family caregivers can delay institutionalization of loved ones and improve a caregiver's own physical and mental well-being—thus reducing costs to families and government. In addition, AFA supports an **appropriation of $5 million for the Alzheimer's Disease Communications Campaign.**

Food and Drug Administration (FDA):

AFA supports FDA funding in FY 2015 that fully restores the agency's base lost in the FY 2013 sequester and provides for a modest additional funding above that level. **Specifically, we are requesting budget authority appropriations of $2.78 billion for FDA, $223 million above FY '14 appropriated spending.**

FDA activities are necessary to ensure proper evaluation and testing of pharmaceutical treatments for Alzheimer's disease before these drugs enter the market. In addition, with the science of this disease becoming more complex, FDA plays an increasingly important and often resource-intensive role in pharmaceutical innovation. AFA's request is in line with the appropriations request being recommended by the Alliance for a Stronger FDA and the Coalition to Accelerate Cure/Treatments for Alzheimer's Disease (ACT-AD).

As we work toward meeting the goal of the historic "National Plan to Address Alzheimer's Disease" to prevent and effectively treat Alzheimer's disease by 2025, adequate resources must be committed to meet the pending challenge. Taken together, these programs represent a lifeline to families who care for a loved one with Alzheimer's disease and provide hope to Americans living with the disease and those who face it in the future that there will be funding for a cure.

AFA thanks the Committee for the opportunity to present its recommendations and looks forward to working with you through the appropriations process. Please contact me or Eric Sokol, AFA's vice president of public policy, at esokol@alzfdn.org if you have any questions or require further information.

Testimony of Stephen C. Shannon, D.O., M.P.H.
President and Chief Executive Officer
American Association of Colleges of Osteopathic Medicine

Concerning the Department of
Health and Human Services Appropriations for Fiscal Year 2015
Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

March 28, 2014

The American Association of Colleges of Osteopathic Medicine (AACOM) strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to the FY 2010 level of $7.48 billion; funding of $520 million for HRSA's Title VII and VIII programs under the Public Health Service Act; $10 million minimally for the Teaching Health Center Graduate Medical Education (THCGME) Development Grants; sustainment of student scholarship and loan repayment programs; $4 million for the Rural Physician Training grants; $3 million for the National Health Care Workforce Commission; $32 billion for the National Institutes of Health (NIH); and $375 million in base discretionary funding, restoring the base to FY 2011 levels for the Agency for Healthcare Research and Quality (AHRQ). AACOM represents the 30 accredited colleges of osteopathic medicine in the United States. These colleges are accredited to deliver instruction at 41 teaching locations in 28 states. In the 2013-14 academic year these colleges are educating over 23,000 future physicians – more than 20% of US medical students. Six of the colleges are publicly controlled; 24 are private institutions.

The Title VII health professions education programs, authorized under the Public Health Service Act and administered through 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.

As demand for health professionals increase in the face of impending shortages combined with faculty shortages across health professions disciplines, racial and ethnic disparities in health care, a growing, aging population, and the anticipated demand for increased access to care, these needs strain an already fragile health care system. AACOM appreciates the investments that have been made in these programs, and **we urge the Subcommittee to fund $520 million for the Title VII and VIII** programs to include support for the following programs in order to include: **the Primary Care Training and Enhancement (PCTE) Program, the Health Careers Opportunity Program (HCOP), the Centers of Excellence (COE), the Geriatric Education Centers (GECs) and the Area Health Education Centers (AHECs).** We strongly oppose the Administration's proposals to eliminate funding for AHECs and the HCOP.

AACOM has serious concerns with the Administration's budget request that would cut nearly $15 billion from **Medicare graduate medical education (GME)**. Because GME funding is critical to addressing the existing physician workforce shortage and ensuring patient access to our nation's health care, AACOM believes that current GME funding should not be sacrificed and simply shifted to other health care workforce programs of importance. Instead, additional investments in GME are critical to an already insufficiently-funded system.

AACOM strongly supports the continuation of the **THCGME Program**, which provides funding to support primary care medical and dental residents training in community-based settings. THCs currently train more than 350 medical and dental residents and are providing

more than 700,000 primary care visits in underserved rural and urban communities. This program will also provide long-term benefits. According to the HRSA, physicians who train in THCs are three times more likely to work in such centers and more than twice as likely to work in underserved areas as physicians who train in other settings. The THCGME Program's five-year authorization expires in FY15, but the recruitment of new residents is being impacted now. **We support an investment of $10 million in FY15 for development grants minimally.**

Through scholarships and loan repayment, **the National Health Service Corps (NHSC)** supports the recruitment and retention of primary care clinicians to practice in underserved communities. Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. The self-reported average medical education debt of graduates of colleges of osteopathic medicine who borrowed to attend medical school has increased by almost $85,000 in the last decade. Today, there are more than 23,000 students enrolled at osteopathic medical schools across the nation. Recent graduates report graduating with an average medical education debt of $211,423.

Today, there are nearly 8,900 NHSC members providing culturally competent care to more than 9.3 million people. Care is provided at 5,100 NHSC-approved health care sites in urban, rural, and frontier areas. In addition to Corps providers currently providing care, nearly 1,100 students, residents, and health providers receive scholarships or participate in the Student to Service Loan Repayment program to prepare to practice, which provides loan repayment assistance to medical students in their last year of education in return for their commitment to practice. **AACOM appreciates the Administration's continued investment in the NHSC and strongly supports the preservation of student scholarship and loan repayment programs. Furthermore, we**

encourage congressional authorizers and appropriators to work together before current mandatory funding for the NHSC expires at the end of FY15.

This critical funding works to address the primary care workforce shortage and advances innovative models of service.

HRSA's **Rural Physician Training grants** will help rural-focused training programs recruit and graduate students most likely to practice medicine in underserved rural communities. HRSA's Office of Rural Health Policy analyzes potential effects of policy on residents of rural communities and administers grant programs designed to build health care capacity at both the local and state levels. Health professions workforce shortages are exacerbated in rural areas, where communities struggle to attract and keep well-trained providers. According to HRSA, approximately 65 percent of primary care health professional shortage areas are rural. **AACOM supports the President's FY15 budget request of $4 million for the Rural Physician Training grants.**

The **National Health Care Workforce Commission** was designed to develop and evaluate training activities to meet demand for health care workers. Without funding, the Commission cannot identify barriers that may create and exacerbate workforce shortages and improve coordination on the federal, state, and local levels. Having this type of coordinating body in place is becoming more critical as more Americans have insurance coverage and as the population ages, requiring access to care. As the United States struggles to address health care provider shortages in certain specialties and in rural and underserved areas, the country lacks a defined policy to address these critical. **For these reasons, AACOM recommends that $3 million be appropriated to fund the Commission so it can begin its important work.**

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 $32 billion 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 vitally 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 (NCCAM) to continue fulfilling this essential research role.

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 will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence; however, more investment is needed. **AACOM recommends $375 million in base discretionary funding, restoring the base to FY 2011 levels for the AHRQ.** This investment will preserve AHRQ's current programs while helping to restore its critical health care safety, quality, and efficiency initiatives.

AACOM is grateful for the opportunity to submit its views and looks forward to continuing to work with the Subcommittee on these important matters.

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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, Education and Related Agencies – March 28, 2014

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 fiscal year 2015 funding levels for programs with a significant impact on the health of rural Americans.

NRHA is a national nonprofit membership organization with a diverse collection of 21,000 individuals and organizations who share a common interest in rural health. 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.

NRHA is advocating support for a group of rural health program that assist rural communities in maintaining and building a strong health care delivery system into the future. Most importantly, these programs help increase the capacity of the rural health care delivery system and true safety net providers. Rural Americans, on average, are poorer, sicker and older than their urban counterparts. Programs in the rural health safety net increase access to health care, help communities create new health programs for those in need and train the future health professionals that will care for the 62 million rural Americans. With modest investments, these programs evaluate, study and implement quality improvement programs and health information technology systems.

Important rural health programs supported by 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 build a program around their needs. These grants award funding to develop needed formal, integrated networks of providers that deliver primary and acute services. The grants have led to projects including information technology networks, oral screenings, and preventative care. 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 five full years after federal funding ended. Request: $62.7 million.

Rural Health Research and Policy Grants form 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. 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. Request: $10.3 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 critical rural health programs. The state offices play a key role in assisting rural health clinics, community health centers, and small, rural hospitals assess community health care needs. This program creates a state focus for rural health interests, brings technical assistance to rural areas, and helps frontier communities tap state and

national resources available for health care and economic development. In partnership with other state agencies, the state rural health offices have been essential in addressing the unique needs of rural communities. Request: $11.1 million.

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects for Critical Access Hospitals (CAHs) across the country. The BBA created this essential program to improve access to essential health care services by CAHs, rural hospital networks and rural emergency medical services. These grants allow statewide coordination and provide expertise to CAHs for quality improvement or information technology activities. 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: $47.7 million.

Rural and Community Access to Emergency Devices assist 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. This program trains lay rescuers and first responders in their use and places them in public areas where sudden cardiac arrest is likely to occur. Request: $3.7 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 hospital care. The OAT leads, coordinates and promotes the use of telehealth technologies by fostering partnerships

between federal agencies, states and private sector groups to create telehealth projects. These approaches are still new and unfolding and continued investment in the infrastructure and development is needed. Request: $15.3 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 and the long-term underserved in isolated rural communities. Programs like the NHSC help maximize the capacity of our health system to care for patients. The demand for primary care providers far exceeds the supply, and the needs of our rural communities continue to grow. The NRHA supports the President's request to ensure that the NHSC has access to the dedicated funding through the CHC Fund.

Frontier Community Health Integration Demonstration Program (F-CHIP) funds development and testing of new models for the delivery of health care services in frontier areas through improving access and integration of the delivery of health care to Medicare beneficiaries.

Frontier Extended Stay Clinic (FESC) a geographically isolated medical clinic designed to provide primary, emergency, and extended-stay care 24 hours per day when hospital services are not readily available. The Federal Office of Rural Health Policy (ORHP) has provided funding for infrastructure development to four clinics in Alaska.

Title VII Health Professions Training Programs (with a significant rural focus):

• **Area Health Education and Centers (AHECs)** financially support and encourage those training to become health care professionals 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. The AHEC Programs and Centers play a critical national role in addressing health care workforce shortages, particularly those in primary care through an established infrastructure. The program grantees support the recruitment and retention of physicians, students, faculty and other primary care providers in rural and medically underserved areas by providing local, community-based, interdisciplinary primary care training. Educating and training rural health care providers ensures a sound future in the delivery of rural health care. It has been estimated that nearly half of AHECs would shut down without federal funding. Request: $75 million.

• **Rural Physician Pipeline Grants** will help medical colleges develop special rural training programs and recruit students from rural communities, who are more likely to return to their home regions to practice. 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: $4.4 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: $36.7 million.

The National Rural Health Association appreciates the opportunity to provide our recommendations to the Subcommittee. These programs are critical to the rural health delivery system and help maintain access to high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of the Subcommittee to continue making these important investments in rural health.

Testimony of the American College of Preventive Medicine
Concerning Fiscal Year 2015 Appropriations
Submitted for the Record to the House Appropriations Subcommittee on
Labor, Health and Human Services, Education, and Related Agencies – March 28, 2014

The American College of Preventive Medicine (ACPM) urges the House 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 **$10 million in FY 2015 for preventive medicine residency training under the public health 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 of $520 million in FY 2015 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

In today's healthcare environment, the tools and expertise provided by preventive medicine physicians play an integral role in ensuring 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 determinants of health and disease. These are the tools employed by preventive medicine physicians who practice at the health system level 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.

Organizations across the spectrum have recognized the growing demand for 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," and the Accreditation Council on Graduate Medical Education (ACGME) recommends increased funding for preventive medicine residency training programs. Additionally, the Association of American Medical Colleges released statements in 2011 that stressed the importance of incorporating behavioral and social sciences in medical education as well as announcing changes to the Medical College Admission Test that would test applicants on their knowledge in these areas. Such measures strongly indicate increasing recognition of the need to take a broader view of health that goes beyond just clinical care—a view that is a unique focus and strength of preventive medicine residency training.

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 and population-based medicine***. Preventive medicine residency training programs provide a blueprint on how to train our future physician workforce; physicians trained to zoom in on individual patient care needs and zoom out to the community and population level to identify and treat the social determinants of health. Preventive medicine physicians have the training and expertise to advance the population health outcomes that public and private payers are increasingly promoting to their providers. These physicians have a strong focus on quality care improvement and ***are at the forefront of efforts to integrate primary care and public health***.

According to the Health Resources and Services Administration (HRSA) and health workforce experts, there are personnel shortages in many public health occupations, including epidemiologists, biostatisticians, and environmental health workers among others. According to the 2012 Physician Specialty Data Book released by the Association of American Medical Colleges, preventive medicine had one of the biggest decrease (-25%) in the number of first-year ACGME residents and fellows between 2005 and 2010. ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. This deficiency in physicians trained to carry out core public health activities 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.

Despite being recognized as an underdeveloped national resource and in shortage for many years, physicians training in the specialty of Preventive Medicine 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.

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. Support for faculty and tuition has been almost non-existent. 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).

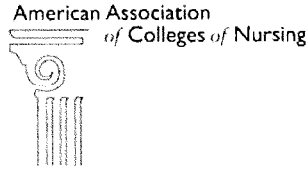
HRSA—as authorized in Title VII of the Public Health Service Act—is a critical funding source for several preventive medicine residency programs, as it represents the largest federal funding source for these programs. HRSA funding ($3.8 million in FY 2014) currently supports only 55 preventive medicine residents across 8 residency training programs. An increase of roughly $6 million will allow HRSA to support nearly 120 new preventive medicine residents.

Of note, the preventive medicine residency programs directly support the mission of the HRSA health professions programs by facilitating practice in underserved communities and promoting training opportunities for underrepresented minorities:

- ***Thirty-five percent*** of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate of almost ***3.5 times*** the average for all health professionals. These physicians are meeting a critical need in these underserved communities.
- ***Nearly one in five*** preventive medicine residents funded through HRSA programs are under-represented minorities, which is almost twice the average of minority representation among all health professionals.
- ***Fourteen percent*** of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty.

In addition to training under-represented minorities and generating physicians who work in medically underserved areas, preventive medicine residency programs equip our society with health professionals and public health leaders who possess the tools and skills needed in the fight against the chronic disease epidemic that is threatening the future of our nation's health and prosperity. Correcting the root causes of this critical problem of chronic diseases will require a multidisciplinary approach that addresses issues of access to healthcare; social and environmental influences; and behavioral choices. ACPM applauds the initiation of programs such as the Community Transformation Grant that take this broad view of the determinants of chronic disease. However, any efforts to strengthen the public health infrastructure and transform our communities into places that encourage healthy choices must include measures to strengthen the existing training programs that help produce public health leaders.

Many of the leaders of our nation's local and state health departments are trained in preventive medicine. Their unique combination of expertise in both medical knowledge and public health makes them ideal choices to head the fight against chronic disease as well as other threats to our nation's health. Their contributions are invaluable. Investing in the residency programs that provide physicians with the training and skills to take on these leadership positions is an essential part of keeping Americans healthy and productive. As such, the American College of Preventive Medicine 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 **$10 million in FY 2015 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act.**



Testimony of the American Association of Colleges of Nursing Regarding Fiscal Year (FY) 2015 Appropriations for the Title VIII Nursing Workforce Development Programs, the National Institute of Nursing Research, and Nurse-Managed Health Clinics

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

Department of Health and Human Services

March 28, 2014

Submitted by Suzanne Miyamoto, PhD, RN, Director of Government Affairs and Health Policy, American Association of Colleges of Nursing

As the national voice for baccalaureate and graduate nursing education, the American Association of Colleges of Nursing (AACN) represents nearly 750 schools of nursing that educate over 425,000 students and employ more than 16,000 full-time faculty members. Collectively, these institutions produce approximately half of our nation's Registered Nurses (RNs) and all nurse faculty, Advanced Practice Registered Nurses (APRNs), and nurse scientists. AACN requests that nursing education, research, and practice are strongly supported in FY 2015 through an investment of $251 million for Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), $150 million for the National Institute of Nursing Research (NINR) within the National Institutes of Health (NIH), and $20 million for the Nurse-Managed Health Clinics (NMHCs) (Title III of the Public Health Service Act). These levels will ensure that our nation's nurses are prepared to care for the growing number of patients requiring a complex range of healthcare services.

Demand for Nursing Care

The Bureau of Labor Statistics' (BLS) publication *Employment Projections for 2012-2022* anticipates

significant growth in the nursing workforce from 2.71 million in 2012 to 3.24 million in 2022. This surge in demand translates to 526,800 nurses, or an increase of 19.4%. When considering the number of job openings for RNs due to the increasing demand for nursing care and replacements in an aging nursing workforce, more than one million nurses will be needed by 2022. In fact, according to the *The U.S. Nursing Workforce: Trends in Supply and Education* released by HRSA in 2013, over the next 10 to 15 years, the nearly 1 million RNs older than age 50—about one-third of the current workforce—will reach retirement age. The retirement decisions of these experienced RNs may be influenced by the pace of economic recovery and have the potential to create a serious deficit in the nursing pipeline.

Moreover, the BLS projects a need for 47,600 additional Nurse Practitioners, Certified Registered Nurse Anesthetists, and Certified Nurse-Midwives (or APRNs) to meet the call for more primary and acute care services, particularly due to the aging baby boomer population and increased access to health insurance coverage. The BLS' *Occupational Outlook Handbook* reported that there will be a 31% increase in this sector of the workforce between 2012-2022. Investments are necessary to educate the RNs and APRNs who will provide the care that Americans need now and in the future.

Title VIII Nursing Workforce Development Programs

For fifty years, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs. Between FY 2006 and 2012 alone, the Title VIII programs supported over 450,000 nurses and nursing students as well as numerous academic nursing institutions and healthcare facilities. 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. Today, the Title VIII programs are essential to ensure the demand for nursing care is met by supporting future practicing nurses and the faculty who educate them.

However, faculty vacancies have repeatedly been cited as a fundamental obstacle to maximizing nursing school enrollment. According to the American Association of Colleges of Nursing's *2013-2014 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing* survey, 78,089 qualified applications were turned away from nursing schools in 2013 alone. A primary barrier to accepting all qualified students at nursing colleges and universities continues to be a shortage of faculty. To counter this disparity, the Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education, provided they serve as faculty for four years after graduation.

The Title VIII programs also increase the number of practicing nurses entering the pipeline and the placement of these nurses into medically-underserved areas. AACN's *Title VIII Student Recipient Survey*, which gathers information annually about Title VIII funding and outcomes related to nursing education and career trajectories, provides evidence on the effectiveness of these programs in recruiting more students to the nursing profession and more importantly, practice in rural and underserved areas. Results of the *2013-2014 Title VIII Student Recipient Survey* included responses from 850 students who noted that these programs played a critical role in funding their nursing education. The survey showed that for 67% of respondents, Title VIII funding impacted their decision to enter nursing school. Moreover, 76% of the students receiving Title VIII funding are able to attend school full-time through this federal support. By facilitating full-time education, the Title VIII programs are helping to ensure that students enter the workforce without delay.

Moreover, personal testimony of several survey respondents revealed that many Title VIII recipients intend to practice in the community in which they were educated, a direct state investment. **AACN respectfully requests $251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in FY 2015.**

National Institute of Nursing Research: Advancing Nursing Science

The healthcare community is investigating methods to improve the delivery of high-quality care in a financially sustainable manner. As one of the 27 Institutes and Centers at the NIH, the NINR is dedicated to providing the healthcare workforce with evidence-based knowledge and resources needed to accomplish this goal. Research conducted at NINR addresses disease prevention and health promotion efforts that improve quality of life and alleviate financial burden on individuals and the system. Specific areas targeted by NINR include chronic illness management, disease prevention, pain management, and care-giver support. Nursing research is a critical compliment to biomedical research as it investigates how to prevent disease and promote healthy living. Moreover, research funded at NINR helps to integrate biology and behavior as well as design new technology and tools. At a time when healthcare needs are changing, nursing care must be firmly grounded in nursing science.

NINR also allocates a generous 6% of its overall budget to the education and training of nurse researchers, many of whom dually serve as nurse faculty within our nation's nursing schools. Increased investments must be made in the scientists that improve healthcare delivery through their groundbreaking discoveries. **AACN respectfully requests $150 million for the NINR in FY 2015.**

Nurse-Managed Health Clinics: Expanding Access to Care

Managed by Advanced Practice Registered Nurses and staffed by an interdisciplinary health provider team, NMHCs provide necessary primary care services to medically-underserved communities and serve as critical access points to keep patients out of the emergency room, saving the healthcare system millions of dollars annually. NMHCs provide care to vulnerable populations in a host of regions of the country, including rural communities, Native American reservations, senior citizen centers, elementary schools, and urban housing developments. These communities are the most susceptible to developing chronic illnesses that create heavy financial burden on patients and the healthcare system. NMHCs aim to reduce disease and create healthier communities through improved patient education and health practices.

Often associated with a school, college, university, department of nursing, federally qualified health center, or independent nonprofit healthcare agency, NMHCs also serve as clinical education training sites for students of nursing, medicine, physical therapy, social work, and ancillary healthcare services. According to AACN, the lack of clinical training sites is often pointed to as a top reason for turning away qualified applications in nursing programs. **AACN respectfully requests $20 million for the Nurse-Managed Health Clinics in FY 2015.**

AACN recognizes that the Subcommittee and Congress will need to make difficult decisions regarding appropriations for Fiscal Year 2015. AACN respectfully requests Congress to continue a strong investment in the health of our nation by providing $251 million for the Title VIII Nursing Workforce Development programs, $150 million for the National Institute of Nursing Research, and $20 million for Nurse-Managed Health Clinics in FY 2015.

Testimony in Support of the State Paid Leave Fund

Submitted to the U.S. House of Representatives Committee on Appropriations

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

Marcia Coné, CEO, Women's Fund of Rhode Island

March 28, 2014

As the CEO of Women's Fund of Rhode Island and on behalf of the other organizations listed below, I respectfully urge the Committee on Appropriations to include the State Paid Leave Fund, administered through the Department of Labor, in the Fiscal Year 2015 Labor, Health and Human Services and Education bill. The bill should include the $105 million funding proposed in the President's budget. The State Paid Leave Fund would create a competitive federal grant fund designed to spur innovation among states interested in creating family and medical leave insurance (FMLI) programs, as well as those with established FMLI programs, and has the potential to help millions of American families, including thousands here in Rhode Island maintain economic security.

Women's Fund of Rhode Island works every day to end gender bias and inequality in our state. We advocate for policy changes that create an equitable Rhode Island. Paid family leave is critically important to creating gender equality because it allows all caregivers – men and women – to address family needs while still providing for their families. For this reason, Women's Fund of Rhode Island spearheaded a coalition, WE CARE RI, that brought employers and advocates together to champion the passage of Temporary Caregiver Insurance, Rhode Island's new paid family leave insurance.

At some point in their working lives, almost all Americans will need to take time off to care for a new baby or adopted child, an ailing child or parent, or their own health. The Family and Medical Leave Act – the only federal law designed to help working people meet the dual demands of job and family – leaves out 40 percent of the workforce and guarantees only unpaid leave, which millions cannot afford to take. And only 12 percent of the U.S. workers currently have access to paid family leave through their employers. That means millions of workers who develop serious health conditions, have seriously ill family members or become parents are forced to choose between what is best for them and their families and income they need to cover basic expenses.

Family and medical leave insurance programs at the state level allow workers to pay a small portion of their wages each week for the guarantee that when they need it, they can receive a percentage of their wages while they have to take extended family or medical leave from work. These programs help working families stay afloat when they need time off to care for an ill family member, a new baby or their own health.

Three states – California, New Jersey and Rhode Island – have created family and medical leave insurance programs. Research has shown that paid leave programs contribute to increased family financial stability and improved child well-being, better workforce outcomes for new parents, reductions in government public assistance expenditures, and cost-savings for businesses.

That's why there is broad support among the business community for paid family and medical leave programs. Businesses understand it's good for their bottom line. California employers report that the program has had a neutral or positive effect on employee productivity, profitability, and turnover, and most employers coordinate their

own benefits with the state's PFL program. A 2011 study of California's FMLI program estimated that it would save employers $89 million a year. A recent Rutgers study shows that New Jersey's FMLI program has saved businesses money by improving employee retention, decreasing turnover costs, and improving productivity.

A federal grant program would help states with one-time start-up costs to develop and implement successful family and medical leave insurance programs that are so needed across the country. Once these insurance programs are up and running they become self-sustaining. Without this federal support, the initial capital needed to design and launch these programs would continue to act as a roadblock, despite broad public support.

This fund would benefit both states considering a family leave and medical insurance program (FMLI) and states with an existing FMLI program. States with established FMLI programs could apply for grants to increase awareness about and utilization of the program by conducting outreach to ensure eligible workers who have been paying into the program are accessing it when they need it. For many states considering programs, access to competitive federal grants that help defray the one-time costs of designing and launching these insurance programs would provide a compelling incentive to states to innovate. In the case of the SPLF, a modest investment at the federal level would translate to significant impact for millions of families' economic security.

In January 2014, Rhode Island established an FMLI program. We've already seen nearly 1,000 applications for caregiving leave, but in order to maximize participation in and benefit from this program, we need to significantly increase outreach and education. There are still too many workers in Rhode Island who do not know about this program, so they can't take advantage of it. Grants could help spread the word and increase utilization

through investments in program brochures, a toll-free help line, a dedicated website, billboards, public service announcements, and other outreach tools.

In sum, there is tremendous support across the country for creating a new State Paid Leave Fund. Nearly a dozen states, including Rhode Island could immediately benefit from federal funds made available through a competitive grant program. I urge you to pass a budget bill with $105 million allocated for the State Paid Leave Fund to help states like Rhode Island with programs that benefit working families, businesses, and the local economy.

Thank you for your consideration,

Women's Fund of Rhode Island

Adoption Rhode Island

Rhode Island - NOW

Rhode Island Kids Count

Rhode Island Parent Information Network

Testimony of Anthony F. (Bud) Rock
President and Chief Executive Officer, Association of Science-Technology Centers
submitted to the House Appropriations Subcommittee
on Labor, Health and Human Services, Education, and Related Agencies
March 28, 2014

Seeking Support for the Following Agencies and Programs in FY 2015:
Department of Education -- STEM Innovation Initiative, Effective Teaching and Learning: STEM, and 21st Century Community Learning Centers
Institute of Museum and Library Services – Office of Museum Services
National Institutes of Health – Science Education Partnership Awards

Introduction

Chairman Kingston, Ranking Member DeLauro, and Members of the Subcommittee, thank you for the opportunity to submit written testimony for the record. My name is Anthony (Bud) Rock, and I serve as the President and Chief Executive Officer of the Association of Science-Technology Centers (ASTC). My testimony today addresses the importance of science, technology, engineering, mathematics (STEM), and health education, and will focus specifically on the fiscal year (FY) 2015 budgets for five specific programs and offices at three Federal agencies over which your Subcommittee has jurisdiction, including: (1) the STEM Innovation Initiative at the Department of Education (ED), which would be funded at $170 million under the President's FY 2015 Budget Request; (2) the Effective Teaching and Learning: STEM program at ED, which would be funded at $149.7 million under the President's FY 2015 Budget Request; (3) 21st Century Community Learning Centers (21st CCLC) program at ED, which would be funded at $1.1 billion under the President's FY 2015 Budget Request; (4) the Office of Museum Services at the Institute of Museum and Library Services (IMLS), which would be funded at $29.6 million under the President's FY 2015 Budget Request; and (5) the Science Education Partnership Award (SEPA) program at the National Institutes of Health (NIH), which would be funded at $18.5 million under the President's FY 2015 Budget Request.

Our Request

On behalf of ASTC and the nearly 400 science centers and museums the Association represents here in the United States, I urge the Subcommittee to continue its strong support for critical education programs within ED, IMLS, and NIH as your work on the Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill for FY 2015 moves forward. **Specifically, I ask you to:**

- **Provide the President's requested level of funding for the STEM Innovation Initiative ($170 million), Effective Teaching and Learning: STEM program ($149.7 million), and the 21st Century Community Learning Centers program ($1.1 billion) at the Department of Education.**
- **Provide the Congressionally-authorized level of funding ($38.6 million) for the Institute of Museum and Library Services' Office of Museum Services.**
- **Provide $20 million—commensurate with the FY 2012 and FY 2013 levels—for the Science Education Partnership Award program at the National Institutes of Health, while investigating the Administration's proposal for joint NIH-ED administration of the program.**

- **Continue to closely examine any proposals that would seek to consolidate and/or reorganize Federal STEM education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.**

Before going into more detail about ASTC and the science center and museum field, I want to first offer a brief snapshot of these Federal programs and why they are so essential.

Department of Education
According to the Administration, the **STEM Innovation** initiative would create a fresh framework for delivering STEM education to more students and more teachers more effectively while reducing fragmentation. ASTC is especially intrigued by the proposed **STEM Innovation Networks** component of the program, as it would provide competitive awards to Local Education Agencies in partnership with institutions of higher education, nonprofit organizations, other public agencies, and businesses to transform STEM teaching and learning. I understand that museums would be among the eligible partners for this program, allowing the very institutions that ASTC represents to further expand their already substantial community impact. I encourage the Subcommittee to support our work by providing $170 million in FY 2015 funding for the STEM Innovation initiative.

The Department's **Effective Teaching and Learning: STEM** program promises to build on the success of the current Mathematics and Science Partnerships (MSP) program and would provide State Education Agencies with formula grants that would allow them to provide their students with more high-quality STEM instruction and support. ASTC members—and the communities they serve—have benefitted from the MSP program, and would welcome the opportunity to become further engaged with high-need schools. I encourage the Subcommittee to include $149.7 million in FY 2015 funding for the Effective Teaching and Learning: STEM program.

For years, the **21st Century Community Learning Centers** program has supported the creation of community learning centers that provide academic enrichment opportunities during non-school hours for children—particularly those students who attend high-poverty and low-performing schools. The 21st CCLC program helps students meet state and local student standards in core academic subjects, such as reading and math; offers students a broad array of enrichment activities that can complement their regular academic programs; and offers literacy and other educational services to the families of participating children. ASTC members across the country have utilized 21st CCLC funding to partner with local school districts in an effort to highlight STEM in afterschool, and I encourage the Subcommittee to continue to support the 21st CCLC program by providing it with $1.1 billion in FY 2015 funding.

Institute of Museum and Library Services
The mission of IMLS is to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement, and the agency provides valuable leadership through research, policy development, and grant making. ASTC members—and the Association itself—have a long history of partnership with IMLS, and have been delighted by the agency's recent focus on STEM learning. IMLS recognizes that libraries and museums are important components in the broad effort to improving STEM learning skills in young people, and ASTC

supports their efforts in this regard. In FY 2015, the agency proposes to continue its funding priority (within current grant programs) for projects that develop new programming models to teach STEM skills to at-risk youth. I ask the Subcommittee to support this effort—and each museum grant program the IMLS offers—by providing the Congressionally-authorized funding level of $38.6 million for the **Office of Museum Services**.

National Institutes of Health and STEM Education Consolidation

NIH's **Science Education Partnership Award** program funds innovative K-12 STEM and informal science education projects and is designed to create partnerships among biomedical and clinical researchers and K-12 teachers, as well as schools, museums and science centers, media experts, and other educational organizations. SEPA resources target state and national K-12 standards for STEM teaching and learning and are rigorously evaluated for effectiveness. To date, Federal funding for SEPA has resulted in approximately 150 projects across the country, each one designed to help to attract young people into biomedical and behavioral science careers and enhance science and health literacy in children and adults. Last year, the Administration proposed terminating the SEPA program as part of the broad effort to consolidate Federal STEM education programs—a proposal that ASTC strongly opposed. I am grateful for the Subcommittee's efforts to restore SEPA funding last year, and encourage you to continue your support for the program by providing $20 million for FY 2015.

With regard to the consolidation plan, while I recognize the importance of creating efficiencies within the Federal government whenever possible, I nevertheless had serious concerns about the proposal to altogether eliminate programs that support informal STEM education. Integral Federal investments, SEPA among them, were slated for elimination, with their associated resources directed to ED, the National Science Foundation (NSF), and the Smithsonian Institution. Again, I sincerely appreciate the Subcommittee's thoughtful consideration of the harmful effect the proposed terminations would have had. For FY 2015, the Administration is offering what they call a "fresh reorganization" of Federal STEM education programs, which I urge the Subcommittee to closely examine. While I am pleased that SEPA is no longer slated for termination, I am anxious to learn more about the idea of joint NIH-ED administration of the program and encourage the Subcommittee to seek details. (I should note that while STEM education programs at the National Aeronautics and Space Administration and the National Oceanic and Atmospheric Administration do not fall under this Subcommittee's jurisdiction, I am troubled that they are once again zeroed-out in the FY 2015 Budget Request.)

About ASTC and Science Centers

The Association of Science-Technology Centers is a global organization providing collective voice, professional support, and programming opportunities for science centers, museums, and related institutions, whose innovative approaches to science learning inspire people of all ages about the wonders and the meaning of science in their lives. Science centers are sites for informal learning, and are places to discover, explore, and test ideas about science, technology, engineering, mathematics, health, and the environment. They feature interactive exhibits, hands-on science experiences for children, professional development opportunities for teachers, and educational programs for adults. In science centers, visitors become adventurous explorers who together discover answers to the myriad questions of how the world works—and why. As Members of this Subcommittee know, it is imperative that we spark an interest in STEM fields at

an early age—a key role for community-based science centers and museums, who often undertake this effort with the aforementioned modest—but important—support from ED, IMLS, and NIH, in addition to other Federal agencies.

ASTC works with science centers and museums to address critical societal issues, locally and globally, where understanding of and engagement with science are essential. As liaisons between the science community and the public, science centers are ideally positioned to heighten awareness of critical issues like agriculture, energy, the environment, infectious diseases, and space; increase understanding of—and exposure to—important and exciting new technologies; and promote meaningful exchange and debate between scientists and local communities.

ASTC now counts 651 members, including 490 operating or developing science centers and museums in 45 countries. Collectively, our institutions garner 93 million visits worldwide each year. Here in the United States alone, our guests—and your constituents—pass through science center doors more than 66 million times to participate in intriguing educational science activities and explorations of scientific phenomena. The recent release of the National Science Board's *Science and Engineering Indicators 2014* generally supports this data, reporting that 58% of Americans said they had visited a zoo, aquarium, natural history museum, or science and technology museum in the 12 months prior to the 2012 survey. *Indicators* also found that:

U.S. residents may also come in contact with science and technology (S&T) through America's rich and diverse informal science and cultural institutions. Many of these institutions actively try to broaden and deepen Americans' intellectual and emotional engagement with science (Bell, Lewenstein, Shouse, and Feder 2009). By offering visitors the flexibility to pursue individual curiosity, such institutions provide exposure to S&T that is well-suited to helping people develop their interests and improve their knowledge, and such institutions can sometimes even change patrons' attitudes.

Science centers come in all shapes and sizes, from larger institutions in big metropolitan areas to smaller centers in somewhat less populated ones. ASTC represents institutions as diverse as the American Museum of Science and Energy in Oak Ridge, Tennessee; the Chabot Space and Science Center in Oakland; the Columbia Memorial Space Center in Downey, California; the Connecticut Science Center in Hartford; the Museum of Science and Industry in Chicago; and the Natural History Museum of Utah in Salt Lake City.

Science Centers as an Integral Part of the Nation's Educational Infrastructure

Science centers are physical—and virtual—places where science and citizens meet. Many have scientists on staff, and some feature research facilities on-site. Through exhibits and programming—like lectures and science cafés—science centers bring current research findings to the public while encouraging discussion and debate of current science issues. More and more, science centers are also getting members of the public involved in research projects themselves.

Our centers reach a wide audience, a significant portion of which are school groups. Here in the U.S., 94% of our members offer school field trips, and we estimate that more than 13 million children attend science centers and museums as part of those groups each year. Field trips, however, are truly just the beginning of what science centers and museums contribute to our country's educational infrastructure, as:

- 92% offer classes and demonstrations
- 90% offer school outreach programs
- 76% offer workshops or institutes for teachers
- 74% offer programs for home-schoolers
- 67% offer programs that target adult audiences
- 65% offer curriculum materials
- 50% offer after-school programs
- 34% offer youth employment programs, and
- 22% offer citizen science projects.

As the Subcommittee knows—there is a strong consensus that improving STEM education is critical to the nation's economic strength and global competitiveness in the 21st century. In order to improve STEM education, of course, we must be willing to draw on a full range of learning opportunities and experiences, including those that occur outside of the classroom. In its report entitled *Learning Science in Informal Environments: People, Places, and Pursuits* (2009), the National Research Council (NRC) of the National Academies said "beyond the schoolhouse door, opportunities for science learning abound..." The NRC found, among other things, that there is ample evidence to suggest that science learning takes place throughout the lifespan and across venues in non-school settings. Furthermore, the report highlighted the role of after-school STEM education in promoting diversity and broadening participation, finding that non-school environments can have a significant impact on STEM learning outcomes in historically underrepresented groups, and that these environments may be uniquely positioned to make STEM education accessible to all.

Conclusion

With this in mind, and while ASTC is fully aware of the significant budget challenges that face this Subcommittee and the nation, I hope you will continue to recognize the important educational offerings science centers and museums make available to students, families, and teachers, along with the essential Federal support they receive from the Department of Education, the Institute of Museum and Library Services, and the National Institutes of Health.

Again, I respectfully request that you provide $170 million in funding for the STEM Innovation Initiative, $149.7 million for the Effective Teaching and Learning: STEM program, and $1.1 billion for the 21st Century Community Learning Centers program at the Department of Education; $38.6 million for the Institute of Museum and Library Services' Office of Museum Services; and $20 million for the Science Education Partnership Award program at the National Institutes of Health, while investigating the Administration's proposal for joint NIH-ED administration of the program. In addition, please continue to closely examine any proposals that would consolidate and/or reorganize Federal STEM education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Thank you once again for your strong support for America's science centers and museums—and for the opportunity to present these views. My staff and I would be happy to respond to any questions or provide additional information as needed by the Subcommittee.

Testimony of Anthony F. (Bud) Rock
President and Chief Executive Officer, Association of Science-Technology Centers
submitted to the House Appropriations Subcommittee
on Labor, Health and Human Services, Education, and Related Agencies
March 28, 2014

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On behalf of ASTC and the nearly 400 science centers and museums the Association represents here in the United States, I urge the Subcommittee to continue its strong support for critical education programs within ED, IMLS, and NIH as your work on the Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill for FY 2015 moves forward. **Specifically, I ask you to:**

- **Provide the President's requested level of funding for the STEM Innovation Initiative ($170 million), Effective Teaching and Learning: STEM program ($149.7 million), and the 21st Century Community Learning Centers program ($1.1 billion) at the Department of Education.**
- **Provide the Congressionally-authorized level of funding ($38.6 million) for the Institute of Museum and Library Services' Office of Museum Services.**
- **Provide $20 million—commensurate with the FY 2012 and FY 2013 levels—for the Science Education Partnership Award program at the National Institutes of Health, while investigating the Administration's proposal for joint NIH-ED administration of the program.**

- **Continue to closely examine any proposals that would seek to consolidate and/or reorganize Federal STEM education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.**

Before going into more detail about ASTC and the science center and museum field, I want to first offer a brief snapshot of these Federal programs and why they are so essential.

Department of Education

According to the Administration, the **STEM Innovation** initiative would create a fresh framework for delivering STEM education to more students and more teachers more effectively while reducing fragmentation. ASTC is especially intrigued by the proposed **STEM Innovation Networks** component of the program, as it would provide competitive awards to Local Education Agencies in partnership with institutions of higher education, nonprofit organizations, other public agencies, and businesses to transform STEM teaching and learning. I understand that museums would be among the eligible partners for this program, allowing the very institutions that ASTC represents to further expand their already substantial community impact. I encourage the Subcommittee to support our work by providing $170 million in FY 2015 funding for the STEM Innovation initiative.

The Department's **Effective Teaching and Learning: STEM** program promises to build on the success of the current Mathematics and Science Partnerships (MSP) program and would provide State Education Agencies with formula grants that would allow them to provide their students with more high-quality STEM instruction and support. ASTC members—and the communities they serve—have benefitted from the MSP program, and would welcome the opportunity to become further engaged with high-need schools. I encourage the Subcommittee to include $149.7 million in FY 2015 funding for the Effective Teaching and Learning: STEM program.

For years, the **21st Century Community Learning Centers** program has supported the creation of community learning centers that provide academic enrichment opportunities during non-school hours for children—particularly those students who attend high-poverty and low-performing schools. The 21st CCLC program helps students meet state and local student standards in core academic subjects, such as reading and math; offers students a broad array of enrichment activities that can complement their regular academic programs; and offers literacy and other educational services to the families of participating children. ASTC members across the country have utilized 21st CCLC funding to partner with local school districts in an effort to highlight STEM in afterschool, and I encourage the Subcommittee to continue to support the 21st CCLC program by providing it with $1.1 billion in FY 2015 funding.

Institute of Museum and Library Services

The mission of IMLS is to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement, and the agency provides valuable leadership through research, policy development, and grant making. ASTC members—and the Association itself—have a long history of partnership with IMLS, and have been delighted by the agency's recent focus on STEM learning. IMLS recognizes that libraries and museums are important components in the broad effort to improving STEM learning skills in young people, and ASTC

supports their efforts in this regard. In FY 2015, the agency proposes to continue its funding priority (within current grant programs) for projects that develop new programming models to teach STEM skills to at-risk youth. I ask the Subcommittee to support this effort—and each museum grant program the IMLS offers—by providing the Congressionally-authorized funding level of $38.6 million for the **Office of Museum Services**.

National Institutes of Health and STEM Education Consolidation

NIH's **Science Education Partnership Award** program funds innovative K-12 STEM and informal science education projects and is designed to create partnerships among biomedical and clinical researchers and K-12 teachers, as well as schools, museums and science centers, media experts, and other educational organizations. SEPA resources target state and national K-12 standards for STEM teaching and learning and are rigorously evaluated for effectiveness. To date, Federal funding for SEPA has resulted in approximately 150 projects across the country, each one designed to help to attract young people into biomedical and behavioral science careers and enhance science and health literacy in children and adults. Last year, the Administration proposed terminating the SEPA program as part of the broad effort to consolidate Federal STEM education programs—a proposal that ASTC strongly opposed. I am grateful for the Subcommittee's efforts to restore SEPA funding last year, and encourage you to continue your support for the program by providing $20 million for FY 2015.

With regard to the consolidation plan, while I recognize the importance of creating efficiencies within the Federal government whenever possible, I nevertheless had serious concerns about the proposal to altogether eliminate programs that support informal STEM education. Integral Federal investments, SEPA among them, were slated for elimination, with their associated resources directed to ED, the National Science Foundation (NSF), and the Smithsonian Institution. Again, I sincerely appreciate the Subcommittee's thoughtful consideration of the harmful effect the proposed terminations would have had. For FY 2015, the Administration is offering what they call a "fresh reorganization" of Federal STEM education programs, which I urge the Subcommittee to closely examine. While I am pleased that SEPA is no longer slated for termination, I am anxious to learn more about the idea of joint NIH-ED administration of the program and encourage the Subcommittee to seek details. (I should note that while STEM education programs at the National Aeronautics and Space Administration and the National Oceanic and Atmospheric Administration do not fall under this Subcommittee's jurisdiction, I am troubled that they are once again zeroed-out in the FY 2015 Budget Request.)

About ASTC and Science Centers

The Association of Science-Technology Centers is a global organization providing collective voice, professional support, and programming opportunities for science centers, museums, and related institutions, whose innovative approaches to science learning inspire people of all ages about the wonders and the meaning of science in their lives. Science centers are sites for informal learning, and are places to discover, explore, and test ideas about science, technology, engineering, mathematics, health, and the environment. They feature interactive exhibits, hands-on science experiences for children, professional development opportunities for teachers, and educational programs for adults. In science centers, visitors become adventurous explorers who together discover answers to the myriad questions of how the world works—and why. As Members of this Subcommittee know, it is imperative that we spark an interest in STEM fields at

an early age—a key role for community-based science centers and museums, who often undertake this effort with the aforementioned modest—but important—support from ED, IMLS, and NIH, in addition to other Federal agencies.

ASTC works with science centers and museums to address critical societal issues, locally and globally, where understanding of and engagement with science are essential. As liaisons between the science community and the public, science centers are ideally positioned to heighten awareness of critical issues like agriculture, energy, the environment, infectious diseases, and space; increase understanding of—and exposure to—important and exciting new technologies; and promote meaningful exchange and debate between scientists and local communities.

ASTC now counts 651 members, including 490 operating or developing science centers and museums in 45 countries. Collectively, our institutions garner 93 million visits worldwide each year. Here in the United States alone, our guests—and your constituents—pass through science center doors more than 66 million times to participate in intriguing educational science activities and explorations of scientific phenomena. The recent release of the National Science Board's *Science and Engineering Indicators 2014* generally supports this data, reporting that 58% of Americans said they had visited a zoo, aquarium, natural history museum, or science and technology museum in the 12 months prior to the 2012 survey. *Indicators* also found that:

U.S. residents may also come in contact with science and technology (S&T) through America's rich and diverse informal science and cultural institutions. Many of these institutions actively try to broaden and deepen Americans' intellectual and emotional engagement with science (Bell, Lewenstein, Shouse, and Feder 2009). By offering visitors the flexibility to pursue individual curiosity, such institutions provide exposure to S&T that is well-suited to helping people develop their interests and improve their knowledge, and such institutions can sometimes even change patrons' attitudes.

Science centers come in all shapes and sizes, from larger institutions in big metropolitan areas to smaller centers in somewhat less populated ones. ASTC represents institutions as diverse as the American Museum of Science and Energy in Oak Ridge, Tennessee; the Chabot Space and Science Center in Oakland; the Columbia Memorial Space Center in Downey, California; the Connecticut Science Center in Hartford; the Museum of Science and Industry in Chicago; and the Natural History Museum of Utah in Salt Lake City.

Science Centers as an Integral Part of the Nation's Educational Infrastructure

Science centers are physical—and virtual—places where science and citizens meet. Many have scientists on staff, and some feature research facilities on-site. Through exhibits and programming—like lectures and science cafés—science centers bring current research findings to the public while encouraging discussion and debate of current science issues. More and more, science centers are also getting members of the public involved in research projects themselves.

Our centers reach a wide audience, a significant portion of which are school groups. Here in the U.S., 94% of our members offer school field trips, and we estimate that more than 13 million children attend science centers and museums as part of those groups each year. Field trips, however, are truly just the beginning of what science centers and museums contribute to our country's educational infrastructure, as:

- 92% offer classes and demonstrations
- 90% offer school outreach programs
- 76% offer workshops or institutes for teachers
- 74% offer programs for home-schoolers
- 67% offer programs that target adult audiences
- 65% offer curriculum materials
- 50% offer after-school programs
- 34% offer youth employment programs, and
- 22% offer citizen science projects.

As the Subcommittee knows—there is a strong consensus that improving STEM education is critical to the nation's economic strength and global competitiveness in the 21st century. In order to improve STEM education, of course, we must be willing to draw on a full range of learning opportunities and experiences, including those that occur outside of the classroom. In its report entitled *Learning Science in Informal Environments: People, Places, and Pursuits* (2009), the National Research Council (NRC) of the National Academies said "beyond the schoolhouse door, opportunities for science learning abound..." The NRC found, among other things, that there is ample evidence to suggest that science learning takes place throughout the lifespan and across venues in non-school settings. Furthermore, the report highlighted the role of after-school STEM education in promoting diversity and broadening participation, finding that non-school environments can have a significant impact on STEM learning outcomes in historically underrepresented groups, and that these environments may be uniquely positioned to make STEM education accessible to all.

Conclusion

With this in mind, and while ASTC is fully aware of the significant budget challenges that face this Subcommittee and the nation, I hope you will continue to recognize the important educational offerings science centers and museums make available to students, families, and teachers, along with the essential Federal support they receive from the Department of Education, the Institute of Museum and Library Services, and the National Institutes of Health.

Again, I respectfully request that you provide $170 million in funding for the STEM Innovation Initiative, $149.7 million for the Effective Teaching and Learning: STEM program, and $1.1 billion for the 21st Century Community Learning Centers program at the Department of Education; $38.6 million for the Institute of Museum and Library Services' Office of Museum Services; and $20 million for the Science Education Partnership Award program at the National Institutes of Health, while investigating the Administration's proposal for joint NIH-ED administration of the program. In addition, please continue to closely examine any proposals that would consolidate and/or reorganize Federal STEM education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Thank you once again for your strong support for America's science centers and museums—and for the opportunity to present these views. My staff and I would be happy to respond to any questions or provide additional information as needed by the Subcommittee.

Testimony Submitted on behalf of the
Association of University Programs in Occupational Health and Safety (AUPOHS)

Jackie Agnew, MPH, PhD
President, Association of University Programs in Occupational Health and Safety
Professor, Department of Environmental Health Sciences
Johns Hopkins Bloomberg School of Public Health

I am testifying on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), an organization representing the 18 multidisciplinary, university-based Education and Research Centers (ERCs) and the ten Agricultural Centers for Disease and Injury Research, Education, and Prevention funded by the National Institute for Occupational Safety and Health (NIOSH), the federal agency responsible for supporting education, training, and research for the prevention of work-related injuries and illnesses in the United States. We respectfully request that the Fiscal Year 2015 Labor, Health and Human Services Appropriations bill include level funding of $27 million for the Education and Research Centers and $24 million for the Agriculture, Forestry and Fishing Program within the NIOSH budget.

The ERCs are regional resources for parties involved with occupational health and safety – industry, labor, government, academia, and the public. Collectively, the ERCs provide training and research resources to every Public Health Region in the United States. ERCs contribute to national efforts to reduce losses associated with work-related illnesses and injuries by offering:

- Prevention Research: Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.
- Professional Training: ERCs support 86 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 18 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.

Occupational injury and illness represent a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, each year nearly 1.2 million workers are injured seriously enough to require time off work and, daily, an average of 11,000 U.S. workers sustain disabling injuries on the job, 13 workers die from an injury suffered at work, and 146 workers die from work-related diseases. This burden costs industry and citizens an estimated $4 billion per *week* -- $250 billion dollars per year. This is an especially tragic situation because work-related fatalities, injuries and illnesses are preventable with effective, professionally directed, health and safety programs.

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% to over 31 million. Work related injury and fatality rates increase at age 45, with rates for workers 65 years and older nearly three times greater than younger workers. In addition to changing demographics, the rapid development of new technologies (e.g., nanotechnology) poses many

unanswered questions with regard to workplace health and safety that require urgent attention.

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 mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize disaster losses. For example, 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 to implement evidence-based programs to safeguard the health of clean-up workers. Additionally, NIOSH is now administering grants to provide health screening of World Trade Center responders. We need manpower to address these challenges and it is the NIOSH ERCs that train the professionals who fill key positions in health and safety programs, regionally and around the nation. And because ERCs provide multi-disciplinary training, ERC graduates protect workers in virtually every walk of life. Despite the success of the ERCs in training such qualified professionals, the country continues to have ongoing manpower shortages.

The Agricultural Safety and Health Centers program was established by Congress in 1990 (P.L. 101-517) in response to evidence that agricultural workers were suffering substantially higher rates of occupational injury and illness than other U.S. workers.

Today the NIOSH Agriculture, Forestry, and Fishing (AFF) Initiative includes ten regional Centers for Agricultural Disease and Injury Research, Education, and Prevention and one national center to address children's farm safety and health. The AFF program is the only

substantive federal effort to meet the obligation to ensure safe working conditions for workers in this most vital production sector. While agriculture, forestry, and fishing constitute one of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are themselves small: nearly 78% employ fewer than 10 workers, and most rely on family members and/or immigrants, part-time, contract and seasonal labor. Thus, many AFF workers are excluded from labor protections, including many of those enforced by OSHA.

In 2012 the AFF sector had a work-related fatality rate of 22 per 100,000 workers, the highest of any sector in the nation. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on farms with fewer than 11 full-time employees. In addition to the harm to individual men, women, and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings. The life-saving, cost-effective work of the NIOSH AFF program is not replicated by any other agency:

- State and federal OSHA personnel rely on NIOSH research in the development of evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the NIOSH AFF program.
- While committed to the well-being of farmers, the USDA has little expertise in the medical or public health sciences. USDA no longer funds, as it did historically, land grant university-based farm safety specialists.
- Staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts *to keep abreast of cutting-edge research* and new directions in this area.

NIOSH Agricultural Center activities include:

AFF research has shown that the use of rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99% of overturn-related deaths. A New York program has increased the installation of ROPS by 10-fold and recorded over 140 close calls with no injuries among farmers who had installed ROPS. 99% of program participants said they would recommend the program to other farmers.

Working in partnership with producers and farm owners, the NIOSH AFF Centers have developed evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.

Commercial Fishing had a reported annual fatality rate 58 times higher than the rate for all U.S. workers in 2009. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. A NIOSH AFF-funded team produced an interactive navigation training CD in three languages, demonstrated the effectiveness of refresher survival drill instruction, and assisted the US Coast Guard's revision of regulations requiring commercial fishing vessel captains complete navigation training.

The Centers have partnered with producers, employers, the federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and health care providers about the best way to treat *and* prevent agricultural injury and illness.

In 2010, the logging industry had a reported fatality rate of 91.9 deaths per 100,000 workers (preliminary data), a rate more than 25 times higher than that of all US workers. NIOSH AFF Centers, including the Southeast and the Northwest, are uniquely positioned to ensure the safety of our nation's 86,000 workers in forestry & logging.

Thank you for the opportunity to present testimony on behalf of the many individuals committed to working to improve the safety and well being of others in our communities.

Statement by the Association of American Medical Colleges on FY 2015 Appropriations for the Department of Health and Human Services Submitted for the Record to House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies - March 28, 2014

The Association of American Medical Colleges (AAMC) is a not-for-profit association representing all 141 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 AAMC requests the following for federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: at least $32 billion for the National Institutes of Health (NIH); $375 million for the Agency for Healthcare Research and Quality (AHRQ); $520 million for the Title VII and VIII health professions workforce programs the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions; and student aid through the Department of Education and HRSA's National Health Service Corps. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

National Institutes of Health – Congress's long-standing bipartisan 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. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments.

Nearly 84 percent of NIH research funding is awarded to more than 2,500 research institutions in every state. At least half of this funding supports life-saving research at America's medical schools and teaching hospitals, where scientists, clinicians, fellows, residents, medical students, and trainees work side-by-side to improve the lives of Americans through research. This successful partnership between the federal government and academic medicine not only lays the foundation for improved health and quality of life, it also strengthens the nation's long-term economy.

The Consolidated Appropriations Act of 2014 included a welcome and much needed increase for NIH. However, this increase did not restore the funding cut from sequestration in FY 2013 or the purchasing power lost over the past decade. The AAMC hopes FY 2014 represents a first step toward restoring our nation's preeminence in medical research. The AAMC supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in our nation's investment in medical research. The AAMC also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic future.

The AAMC notes the Subcommittee's past proposals to reduce the limit on salaries that can be drawn from NIH extramural awards to Executive Level III of the Federal Executive Pay Scale. These proposals come at a time when medical schools' and teaching hospitals' diseretionary funds from clinical revenues and other sources have become increasingly constrained and less

available to invest in research. As institutions and departments divert funds to compensate for the reduction in the salary limit, they have less funding for critical activities such as bridge funding to investigators between grants and start-up packages to young investigators to launch their research programs. The lower salary cap also will disproportionately affect physician investigators, who will be forced to make up salaries from clinical revenues, thus leaving less time for research. This may serve as a deterrent to their recruitment into research careers. The AAMC urges the Subcommittee to retain the limit at Executive Level II.

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, evidence-based, efficient, and cost-effective health care to all of its citizens. The AAMC joins the Friends of AHRQ in recommending $375 million in base discretionary funding for the agency in FY 2015.

As the only federal agency with the sole purpose of generating evidence to make health care safer; higher quality; and more accessible, equitable, and affordable, AHRQ also works to ensure such evidence is available across the continuum of health care stakeholders, from patients to payers to providers. 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.

Health Professions Funding – HRSA's Title VII health professions and Title VIII nursing education programs are the only federal programs designed to improve the supply, distribution, and diversity of the nation's health care workforce. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces. The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending $520 million for these important workforce programs in FY 2015.

Throughout their 50-year history, the Title VII and Title VIII programs have helped the workforce adapt to meet the nation's changing health care needs. This funding level is necessary to ensure continuation of all Title VII and Title VIII programs while also supporting promising initiatives such as the Pediatric Subspecialty Loan Repayment program, the Clinical Training in Interprofessional Practice program, the Rural Physician Training Grants, and other efforts to bolster the workforce. The AAMC strongly objects to the Administration's proposal to eliminate the Area Health Education Centers (AHEC), which, in 2012 alone, trained more than 20,000 health professions students in community-based settings, and the Health Careers Opportunity Program (HCOP), which research shows has helped students from disadvantaged backgrounds achieve higher grade point averages and matriculate into health professions programs. Continued support for these and the full spectrum of Title VII and programs is essential to prepare our next generation of medical professionals to adapt to the evolving health care needs of the changing population.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Professions also supports the Children's Hospitals Graduate Medical Education (CHGME) program. This program

provides critical federal graduate medical education support for children's hospitals to prepare the future primary care and specialty care workforce for our nation's children. At a time when the nation faces a critical physician shortage, the AAMC has serious concerns about the proposed elimination of the CHGME program in the president's budget. We strongly support full funding for the Children's Hospitals Graduate Medical Education program at $300 million in FY 2015.

Student Aid and the National Health Service Corps (NHSC) – The AAMC urges the committee to sustain student loan and repayment programs for graduate and professional students at the Department of Education. The average graduating debt of medical students is currently $175,000, and typical repayment can range from $326,000 to $492,000.

The AAMC urges Congress to reauthorize the National Health Service Corps (NHSC) Fund, created under the Affordable Care Act (ACA, P.L. 111-142 and P.L. 111-152) and set to expire in FY 2015. In the absence of continued mandatory funding, the committee must address the NHSC funding shortfall in the already strained Labor-HHS spending bill. To date, the steady, sustained, and certain growth established by this mandatory funding for the NHSC has resulted in program expansion and innovative pilots such as the Student to Service (S2S) Loan Repayment Program that incentivizes fourth-year medical students to practice primary care in underserved areas after residency training.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee as it prepares its FY 2015 spending bill.

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, Education, and Related Agencies – March 28, 2014

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record recommending **$520 million in FY 2015 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 national organizations (https://www.aamc.org/advocacy/hpnec/members.htm) dedicated to ensuring the health care workforce is trained to meet the needs of the country's growing, aging, and diverse population.

Titles VII and VIII are the only federally-funded programs that seek to improve the supply, distribution, and diversity of the health professions workforce, with a focus on primary care and interdisciplinary training. By providing educational and training opportunities to aspiring and practicing health professionals, the programs also play a critical role in helping the workforce adapt to meet the nation's changing health care needs. The programs prepare health professionals for new care delivery models and emerging health care challenges, enhance the size and diversity of the health care workforce, and improve access to primary care for children, adults, and seniors.

While HPNEC recognizes the Subcommittee faces difficult decisions in a constrained budget environment, a continued commitment to programs supporting health care workforce development should remain a high priority. The nation faces a shortage of health professionals, which will be exacerbated by the addition of millions of Americans to the health care system. Failure to fully fund the Title VII and Title VIII programs would jeopardize activities to fill these vacancies and to prepare the next generation of health professionals.

The Title VII and Title VIII programs can be considered in seven general categories:

- The **Primary Care Medicine and Oral Health Training** programs support education and training of primary care professionals, to improve access and quality of health care in underserved areas. Two-thirds of Americans interact with a primary care provider every year. Over one-third of primary care providers trained through these programs work in underserved areas, compared to 10 percent of those trained in other programs. The *General*

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Pediatrics, *General Internal Medicine,* and *Family Medicine* programs provide critical funding for primary care physician training in community-based settings and support a range of initiatives, including medical student and residency training, faculty development, and the development of academic administrative units. The *Rural Physician Training Grants* focuses on increasing the number of medical school graduates practicing in rural communities. 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. The *General Dentistry, Pediatric Dentistry, and Public Health Dentistry* programs provide grants to dental schools and hospitals to create or expand primary care and public health dental residency training programs.

- Because much of the nation's health care is delivered in remote areas, the **Interdisciplinary, Community-Based Linkages** cluster supports community-based training of health professionals. These programs are designed to encourage health professionals to return to such settings after completing their training and to encourage collaboration between two or more disciplines. The *Clinical Training in Interprofessional Practice* program supports interdisciplinary training opportunities preparing providers to deliver quality, coordinated, and efficient care. The *Area Health Education Centers (AHECs)* offer 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 leverage 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, all designed to bolster the number and quality of health care providers caring for older generations. The *Graduate Psychology Education* program, which supports interdisciplinary training of doctoral-level psychology students with other health professionals, provides 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 *Mental and Behavioral*

Health Education and Training Grant Program supports the training of psychologists, social workers, and child and adolescent professionals. These programs together work to close the gap in access to quality mental and behavioral health care services by increasing the number of qualified health providers.

- The **Minority and Disadvantaged Health Professionals Training** cluster helps improve health care access in underserved areas and the representation of minority and disadvantaged individuals in the health professions. Diversifying the health care workforce is a central focus of the programs, making them a key player in the fight to mitigate racial, ethnic, and socio-economic health disparities. Further, the programs emphasize cultural competency for all health professionals, an important role as the nation's population is growing and becoming increasingly diverse. *Minority Centers of Excellence* support 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 **Health Professions Workforce Information and Analysis** program provides grants to institutions to collect and analyze data to advise future decision-making on the health professions and nursing programs. The *Health Professions Research and Health Professions Data* programs have developed valuable, policy-relevant studies on the distribution and training of health professionals. The *National Center for Workforce Analysis* performs research and analysis on health workforce issues, including supply and demand, to help inform both public and private decision-making.
- The **Public Health Workforce Development** programs help increase the number of individuals trained in public health, 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 do not receive funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. This cluster also includes a focus on loan repayment as an incentive for health professionals to practice in disciplines and settings experiencing shortages. The *Pediatric Subspecialty Loan Repayment Program* offers loan repayment for pediatric medical subspecialists, pediatric surgical specialists, and child and adolescent mental and behavioral health specialists, in exchange for service in underserved areas.

- 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 that, between FY 2006 and 2012, supported over 450,000 nurses and nursing students as well as numerous academic nursing institutions and health care facilities. 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 nurses with advanced education, including clinical nurse specialists, nurse practitioners, certified nurse-midwives, nurse anesthetists, public health nurses, nurse educators, and nurse administrators. *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 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 exchange for 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 disadvantaged health professions students. The *NURSE Corps* supports undergraduate and graduate nursing students with a preference for those with the greatest financial need. The *Primary Care Loan* (PCL) program provides loans in return for dedicated service in primary care. The *Health Professional Student Loan* (HPSL) program provides loans for financially needy health professions students based on institutional determination. These 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 institutions to make loans to disadvantaged students.

The Title VII and Title VIII programs improve the supply, distribution, and diversity of the nation's health professionals. The programs connect individuals to health professions careers, helping individuals in reaching their goals and communities in filling their health needs. The multi-year nature of health professions education and training, coupled with provider shortages across many disciplines and in many communities, necessitate a strong, continued, and reliable commitment to the Title VII and Title VIII programs.

While HPNEC members understand the budget limitations facing the Subcommittee, we respectfully urge support for **$520 million** for the Title VII and VIII programs. We look forward to working with the Subcommittee to prioritize the health professions programs in FY 2015 and into the future.

Statement by the Ad Hoc Group for Medical Research on
FY 2015 Appropriations for the National Institutes of Health
Submitted for the record on March 28, 2014, to the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

The Ad Hoc Group for Medical Research is a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. We appreciate the opportunity to submit this statement in support of enhancing the federal investment in biomedical, behavioral, social, and population-based research conducted and supported by the National Institutes of Health (NIH). The Consolidated Appropriations Act of 2014 included a welcome and much needed increase for the NIH. However, this increase did not restore all of the funds cut by sequestration in FY 2013 or the purchasing power NIH has lost over the past decade due to inflation. We hope FY 2014 represents a first step toward restoring our nation's preeminence in medical research. The Ad Hoc Group for Medical Research recommends that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in our nation's investment in medical research. The Ad Hoc Group also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic future.

The Ad Hoc Group is deeply grateful to the Subcommittee for its long-standing and bipartisan leadership in support of NIH. We continue to believe that science and innovation are essential if we are to continue to improve our nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy.

NIH: A Public-Private Partnership to Save Lives and Provide Hope

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly-productive relationship, leveraging the full strength of our nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every state.

The federal government has an irreplaceable role in supporting medical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge research necessary to yield new innovations and technologies of the future.

Research funded by NIH has contributed to nearly every medical treatment, diagnostic tool, and medical device developed in modern history, from a new treatment for cystic fibrosis to an awareness campaign that resulted in a dramatic decrease in the number of infants lost to Sudden Infant Death Syndrome to a new vaccine to prevent cervical cancer. We are all enjoying longer, healthier lives thanks to the federal government's wise investment in this lifesaving agency. Examples of recent clinical breakthroughs made by NIH-supported scientists include:

- NIH-funded researchers have discovered a way to harness the body's own immune system to fight cancer. The promising results in both adults and children with leukemia lead Science Magazine to name Cancer Immunotherapy as the 2013 Breakthrough of the Year for all of science;
- NIH scientists have developed new treatments for hepatitis C – the leading reason of liver transplants in the U.S. – that have shortened treatment times and produced cures in 85 to 95 percent of patients, even those with advanced disease;
- NIH-funded researchers found that certain molecules in urine can provide an early sign of kidney transplant rejection, a test that allow doctors to act earlier to protect transplanted kidneys;

- An NIH-supported clinical trial demonstrated that an intensive early behavioral intervention delivered before the age of two years can improve symptoms as well as normalize brain activity in some children with autism; and
- NIH-funded scientists developed an innovative method to quickly identify antibiotics that can treat multidrug-resistant bacteria—and reveal how these bacteria-killing medications work.

For patients and their families, NIH is the "National Institutes of Hope."

NIH is the world's premier supporter of merit-reviewed, investigator-initiated basic research. This fundamental understanding of how disease works and insight into the cellular, molecular, and genetic processes underlying life itself, including the impact of social environment on these processes, underpin our ability to conquer devastating illnesses. The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Ensuring a steady pipeline of basic research discoveries while also supporting the translational efforts absolutely necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH.

The research supported by NIH drives not only medical progress but also local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries. According to a report released by United for Medical Research, a coalition of scientific advocates, institutions and industries, in fiscal year 2011, NIH-funded research supported an estimated 432,000 jobs all across the United States, enabled 13 states to experience job growth of more than 10,000 jobs, and generated more than $62 billion in new economic activity.

Stagnant Funding Threatens Scientific Momentum

Despite the increase provided in the current year, over the past decade NIH has lost more than 22 percent of its budget after inflation, significantly impacting the nation's ability to sustain the scientific momentum that has

contributed so greatly to our nation's health and our economic vitality. The leadership and staff at NIH and its Institutes and Centers has engaged patient groups, scientific societies, and research institutions to identify emerging research opportunities and urgent health needs, and has worked resolutely to prioritize precious federal dollars to those areas demonstrating the greatest promise. But a continued erosion of our national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

Perhaps one of the greatest concerns is the obstacle these continued cuts will present to the next generation of scientists, who will see training funds slashed and the possibility of sustaining a career in research diminished. NIH plays a significant role in supporting the next generation of innovators, the young and talented scientists and physicians who will be responsible for the breakthroughs of tomorrow.

The challenges of maintaining a cadre of physician-scientists to facilitate translation of basic research to human medicine, ensuring a biomedical workforce that reflects the racial and gender diversity of our citizenry, and maximizing our nation's human capital to solve our most pressing health problems will only be addressed through continued support of NIH.

NIH is Critical to U.S. Competitiveness

Our country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and cuts of sequestration, which jeopardize our competitive edge in an increasingly innovation-based global marketplace.

Other countries have recognized the critical role that biomedical science plays in innovation and economic growth and have significantly increased their investment in biomedical science. Between 1999 and 2009, Asia's share (including China, India, Japan, Malaysia, Singapore, South Korea, Taiwan, and Thailand) of

worldwide research and development (R&D) expenditures grew from 24 percent to 32 percent, while U.S. R&D expenditures declined from 38 percent to 31 percent. While the U.S. currently leads the world in R&D spending, China's increasing investment in R&D is projected to close the gap and surpass the U.S. in total R&D spending by about 2022. The European Commission also has recently urged its member nations to increase their investment in research substantially, recommending budgets of €80 billion (equivalent to $108 billion) from 2014 to 2020, a 40 percent increase over the previous seven-year period.

This shift in funding raises the concern that talented medical researchers from all over the world, who once flocked to the U.S. for training and stayed to contribute to our innovation-driven economy, are now returning to better opportunities in their home countries. We cannot afford to lose that intellectual capacity, much less the jobs and industries fueled by medical research. The U.S. has been the global leader in medical research because of Congress's bipartisan recognition of NIH's critical role. To maintain our dominance, we must reaffirm this commitment to provide NIH the funds needed to maintain our competitive edge.

NIH: An Answer to Challenging Times

The Ad Hoc Group's members recognize the tremendous challenges facing our nation's economy and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Nevertheless, we believe strongly that NIH is an essential part of the solution to the nation's economic restoration. Strengthening our commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy.

Therefore, the Ad Hoc Group for Medical Research recommends that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in our nation's investment in medical research.

Testimony of the National Violence Prevention Network
Concerning Fiscal Year 2015 Appropriations
Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – March 28, 2014

Thank you for this opportunity to submit testimony in support of increased funding for the National Violent Death Reporting System (NVDRS), which is administered by the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC). The National Violence Prevention Network, a broad and diverse alliance of health and welfare, suicide and violence prevention, and law enforcement advocates supports increasing the FY 2015 funding level to $25 million to allow for nationwide expansion of the NVDRS program. FY 2014 NVDRS funding is $11.2 million.

BACKGROUND

Each year, about 55,000 Americans die violent deaths. In addition, an average of 105 people (22 of which are military veterans) take their own lives each day.

The NVDRS program makes better use of data that are already being collected by health, law enforcement, and social service agencies. The NVDRS program, in fact, does not require the collection of any new data. Instead it links together information that, when kept in separate compartments, is much less valuable as a tool to characterize and monitor violent deaths. With a clearer picture of why violent deaths occurs, law enforcement, public health officials and others can work together more effectively to identify those at risk and target effective preventive services.

Currently, NVDRS funding levels only allow the program to operate in 18 states, including **Alaska, Colorado, Georgia, Kentucky, Maryland, Massachusetts, Michigan, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Utah, Virginia**, and **Wisconsin**. Several other states have expressed an interest in joining once new funding becomes available. While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 18 participating states, non-participating states continue to miss out on the benefits of this important public health surveillance program.

NVDRS IN ACTION

Child abuse and other violence involving children and adolescents remains a problem in America, and it is only through a comprehensive understanding of its root causes that these needless deaths can be prevented. Studies suggest that between 3.3 and 10 million children witness some form of domestic violence annually. Additionally, 1,560 children died as a result of abuse or neglect in 2010.

Children are most vulnerable and most dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at the greatest risk of homicide in their own homes. Combined NVDRS data from **Alaska, Maryland, Massachusetts, New Jersey, Oregon, South Carolina**, and **Virginia** determined that African American children aged four years old and under are more than four times more likely to be victims of homicide than Caucasian children, and that homicides of children aged four and under are most often committed by a parent or caregiver in the home. The data also shows that household items, or "weapons of opportunity," were most commonly used, suggesting that poor stress responses may

be factors in these deaths. Knowing the demographics and methods of child abusers can lead to more effective, targeted prevention programs.

Intimate partner violence (IPV) is another issue where NVDRS is proving its value. While IPV has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. Intimate partner homicides accounted for 30 percent of the murders of women and five percent of the murders of men in 2006, according to the Bureau of Justice Statistics.

Despite being in its early stages in several states, NVDRS is already providing critical information that is helping law enforcement and health and human service officials allocate resources and develop programs in ways that target those most at risk for intimate partner violence. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect, and a substantial number of victims were the suspect's children. In addition, NVDRS data indicate that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and most of these incidents occurred in the women's homes.

NVDRS & VA SUICIDES

Although it is preventable, every year more than 38,000 Americans die by suicide and another one million Americans attempt it, costing more than $36 billion in lost wages and work productivity. In the United States today, there is no comprehensive national system to track suicides. However, because NVDRS includes information on all violent deaths – including

deaths by suicide – information from the system can be used to develop effective suicide prevention plans at the community, state, and national levels.

The central collection of this data can be of tremendous value for organizations such as the Department of Veterans Affairs that are working to improve their surveillance of suicides. For instance, CDC determined from national NVDRS data that veterans comprised 20% of all suicide victims. The types of data collected by NVDRS including gender, blood alcohol content, mental health issues, physical health issues, and intimate partner violence can help prevention programs better identify and treat at-risk individuals.

FEDERAL ROLE NEEDED

At an estimated annual cost of $25 million for full implementation, NVDRS is a relatively low-cost program that yields high-quality results. While state-specific information provides enormous value to local public health and law enforcement officials, data from all 50 states, the U.S. territories and the District of Columbia must be obtained to complete the national picture. Aggregating this additional data will allow us to analyze national trends and also more quickly and accurately determine what factors can lead to violent death so that we can devise and disseminate strategies to address those factors.

STRENGTHENING AND EXPANDING NVDRS IN FY 2014

The 2014 Consolidated Appropriations Act recognized the public health utility of NVDRS in preventing violent deaths and increased NVDRS funding by roughly $8 million to facilitate continued expansion of the NVDRS program. With this new funding, NVDRS will expand to

roughly two-thirds of the country. The time is now to complete the nation-wide expansion of NVDRS by providing an appropriation of $25 million in FY 2015.

We thank you for the opportunity to submit this statement for the record. The investment in NVDRS has already begun to pay off, as the 18 participating states are adopting effective violence prevention programs. We believe that national implementation of NVDRS is a wise public health investment that will assist state and national efforts to prevent deaths from domestic violence, veteran suicide, teen suicide, gang violence and other violence that affects communities around the country. We look forward to working with you secure an FY 2015 NVDRS appropriation of $25 million.

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WRITTEN TESTIMONY IN SUPPORT OF INCREASED FISCAL YEAR (FY) 2015 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 HOUSE COMMITTEE ON APPROPRIATIONS

March 28, 2014

EXECUTIVE SUMMARY

ARVO requests Fiscal Year (FY) 2015 NIH and National Eye Institute (NEI) funding of $32 billion and $730 million, respectively. Such funding would fully restore the $1.7 billion FY2013 sequester cut and provide modest growth. This request improves on the President's proposal to increase NIH and NEI funding by $200 million and $1 million over FY2014, respectively.

- $32 billion NIH funding is critical for supporting Research Project Grants, as the number of RPGs awarded in FY2013 was 20 percent less than in FY2003. R01s, or investigator-initiated grants, have been affected even more dramatically, as the number awarded fell by 34 percent between FY2003 and FY2013.

- NIH-funded basic and clinical research has helped to understand the basis of disease, thereby resulting in innovations in healthcare to save and improve lives. Its research serves an irreplaceable role the private sector could not duplicate.
- As an economic driver, in FY2011NIH-funded research supported 432,000 jobs across the United States and generated more than $62 billion in new economic activity. Every $1 of NIH funding generates $2.21 in local economic growth.
- The U.S. must capitalize on previous investment to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and maintain leadership in the global economy.

$730 MILLION FY2015 FUNDING ENABLES NEI TO PURSUE ITS PRIMARY "AUDACIOUS GOAL" OF RESTORING VISION

At NEI's *Audacious Goals Development* meeting, more than 200 attendees reflecting every sector of the vision community, including government scientists and regulators from various disciplines, discussed topics built around the ten winning submissions from a pool of nearly 500 entries selected through NEI's *Audacious Goals in Vision Research and Blindness Rehabilitation Challenge*. This initiative, conducted by NEI with its National Advisory Eye Council (NAEC) and through *The America Competes Act,* yielded such ideas as restoring light sensitivity to the blind through gene-based therapies and visual prosthetics, pinpoint correction of defective genes, and growing healthy tissue from stem cells for ocular tissue transplants.

In consultation with the NAEC, the NEI converged on its primary Audacious Goal for vision research: **To Regenerate Neurons and Neuronal Connections in the Eye**

and Visual System." In terms of what this would mean for some common eye diseases:

- For AMD, it means the development of light-sensitive photoreceptor cells and their placement into the retina of individuals who are blind from the disease.
- For glaucoma, it means the development of new retinal ganglion cells which would then be transplanted into the retina of individuals with vision loss.

As NEI Director Paul Sieving, M.D., Ph.D. stated in February 2014:

> "The goals are bold but achievable. They are beyond what medicine currently can do. We are planning for a 10-12-15 year effort to reach these endpoints. Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases."

FLAT NIH/NEI BUDGETS HAVE HURT THE U.S. SCIENTIFIC WORKFORCE

The health of the entire U.S. research community is at stake after the flat NIH/NEI funding of the past 11 years. Not only has funding for new investigators been squeezed, but also that of seasoned investigators. This scenario threatens the continuity of research and the retention of trained staff. If an institution needs to let staff go, that means a highly-trained person is lost to another area of research, another institution in a different state, or even another country, if not lost entirely by changing careers or retiring early.

With the vicious funding situation only exasperated by the 2013 sequester, ARVO members have been sharing how the funding environment has affected them. Andrew Pucker, graduate student at Ohio State University (OSU), says:

> "The OSU College of Optometry currently has limited NIH funding, which has led to most of our Ph.D. students being required to spend over 50% of their time teaching instead of completing their coursework and research. **We had to lay off our study coordinators, one of our statisticians, and several of our research staff members**. Also, the harsh funding rates have made it difficult for new faculty members to achieve tenure."

Mary Ann Stepp, Ph.D., Professor of Anatomy and Regenerative Biology at George Washington University, worries about the effects of budget cuts on young female scientists:

> "Tenure protects fewer and fewer faculty these days. Women have made great strides over the past 20-30 years, but **will young women faculty be able to weather these hard times**? More likely than men to have taken time off to have kids or take care of aging parents, they are more likely to be non-tenured and vulnerable. I am just not sure what the future of research is going to look like in 10 or 20 years. **I am glad I am not starting out now myself**."

Finally, University of California, Los Angeles (UCLA) Professor of Ophthalmology Michael Gorin, Ph.D., describes just how hard it has become to perform government-supported science:

> "**We have reached a point at which most [scientists] have a better chance of winning a hand of solitaire than they do of getting a [NIH] grant**. The degree

of uncertainty is having an enormous impact on American science. Our most experienced researchers are looking to exit this competitive environment since it is so exhausting, stressful and detracts them from doing the actual research. The brilliant talent that we used to recruit from around the world are less likely to come here to train (and there are less labs to train them), and those whom we have trained are increasingly returning to their home countries where they are competing directly with the American research enterprise. We are no longer attracting young Americans to go into biomedical research and we are destroying our future group of investigators. Finally, we are losing incredible opportunities to fill in the vast gaps in our knowledge to both understand the diseases that confront the American people and find more effective therapies."

ARVO URGES CONGRESS TO FUND NIH AT $32 BILLION AND NEI AT $730 MILLION IN FY2015 TO FACILITATE MODEST GROWTH, ENSURE THE MOMENTUM OF RESEARCH, RETAIN TRAINED PERSONNEL, AND MAINTAIN U.S. LEADERSHIP IN BIOMEDICAL AND VISION RESEARCH

ABOUT ARVO

ARVO is a community of 12,000 vision researchers from 80 countries; we are the largest, most respected vision research organization in the world. Our aim to advance research worldwide into understanding the visual system and into preventing, treating and curing its disorders.

Submitted on behalf of Kim E. Barrett, Ph.D., President, American Physiological Society

The American Physiological Society (APS) thanks the subcommittee for its ongoing support of 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. The APS urges you to make every effort to provide the NIH with a net funding level of $32 billion in FY 2015. This is necessary to prevent further erosion of research capacity.

Federal investment in research is critically important because breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. The federal government is the primary funding source for discovery research through competitive grants awarded by the NIH. Although the private sector partners with academic researchers to develop research findings into new treatments, industry relies upon federally funded research to identify where innovation opportunities can be found. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. However, this position of leadership is at risk as other nations, including China, increase their investments in research and development while the United States investment has lagged in recent years.

Federal research dollars also have a significant impact at the local level: Approximately 85% of the NIH budget is awarded throughout the country to researchers who use grant funds to pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research.

NIH funds outstanding science

As a result of improved health care, Americans in the 21st century are living longer and healthier lives than ever before. However, chronic conditions such as cardiovascular disease, diabetes, respiratory illnesses, Alzheimer's and cancer continue to inflict a heavy burden in the United States and around the world. As the U.S. population ages, the prevalence and cost of these diseases will increase exponentially. The NIH invests heavily in basic research to understand the physiological mechanisms at work in health and disease. This knowledge is crucial to the development of safe and effective interventions and prevention strategies.

Exciting new initiatives are underway at the NIH to advance science, including the Brain Research through Advancing Innovative Neurotechnologies ("BRAIN") initiative and the Big Data 2 Knowledge project (BD2K). The BRAIN initiative will bring together researchers from diverse disciplines to tackle major gaps in current knowledge about the brain and brain diseases. BD2K will explore ways to capitalize on the immense volume of data being created by biomedical scientists, ultimately enhancing the work of the entire community by providing new tools and resources to make better use of that data. These important projects require significant resources, and at a time of constrained budgets, that will further diminish funding for investigator-initiated grants. The NIH system of allowing investigators to develop and propose ideas which are then evaluated by their peers and selected for funding based on their merit has fostered a research enterprise that is second to none. Increasing the NIH budget to $32 billion would provide funding for large projects as described above, while also providing resources for individual scientists to pursue creative new avenues of research.

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 pressures placed on the biomedical research enterprise after years of sub-inflationary budget increases were severely compounded by sequestration cuts in FY 2013. One analysis showed that NIH supported approximately 1000 fewer investigators in FY 2013 as a result of its declining budget.[1] Researchers who lose their funding face an uncertain future as there are few options to sustain their research without federal grants. Losing federal support puts at risk the investment that it took to build those programs over many years. It also means that talented individuals working in those labs will have to look elsewhere for increasingly scarce jobs. As a result of stagnant funding for NIH, scientists at all stages of their careers struggle to maintain their research programs.

Scientists in the early stages of their careers face a particular set of challenges as they work to establish themselves during a time of dwindling resources. To address some of these problems, the NIH is continuing its commitment to fund new investigators at approximately the same rate as established investigators. The NIH is also developing three new efforts to ensure a diverse and sustainable future biomedical workforce. The National Research Mentoring Network (NRMN) and the Building Infrastructure Leading to Diversity (BUILD) initiative are complementary programs that will develop innovative new mentorship programs to engage individuals from diverse backgrounds and help them prepare to succeed in biomedical research careers. The Coordination and Evaluation Center (CEC) will play a role in coordinating and assessing NRMN

and BUILD, providing program-wide goals and tools to assess progress. These efforts are critical to helping young scientists launch their careers. However, to sustain a talented workforce the NIH needs predictable and sustainable budget growth. If the current funding crisis is not resolved, the continued loss of senior researchers will begin to erode the pool of experienced mentors for early career scientists on which the BUILD and NRMN programs rely.

The NIH also uses the Institutional Development Award (IDeA) Program to broaden the geographic distribution of NIH funds by providing support to researchers and institutions in areas that have not previously received significant NIH funding. IDeA builds research capacity and improves competitiveness in those states by developing shared resources, infrastructure and expertise. Networks established through this program expand research opportunities for students and faculty at predominantly undergraduate institutions and enhance the level of science and technology knowledge of the workforce in IDeA states. The program currently serves institutions and researchers in 23 states and Puerto Rico. The APS believes this program is an important way to broaden participation in the scientific workforce.

The APS appreciates the support of the committee in continuing the Science Education Partnership Awards (SEPA) program at the NIH. This program was slated for elimination last year under the proposed consolidation of science education programs across federal agencies. The SEPA program fosters important connections between biomedical researchers and K-12 students and teachers, providing an opportunity for students at the earliest levels to learn about STEM careers. No other federal STEM program addresses biomedicine or provides this kind of outreach concerning what NIH does to promote the health of our citizens. Thus, SEPA programs

promote health literacy among young individuals, who will increasingly be expected to manage their own health care. Many of the programs sponsored by SEPA, including those at the APS, disproportionately reach underrepresented and disadvantaged students. The APS believes that the SEPA program helps establish the groundwork to address issues of workforce diversity and health literacy.

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 more than 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.

The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with no less than $32 billion in FY 2014.[2]

[1] http://www.asbmb.org/asbmbtoday/201403/PresidentsMessage/

[2] www.faseb.org/fundingreport

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STATEMENT OF
THE AMERICAN THORACIC SOCIETY
submitted to
THE HOUSE LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION APPROPRIATIONS SUBCOMMITTEE
FISCAL YEAR 2014 LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION APPROPRIATIONS BILL
DEPARTMENT OF HEALTH AND HUMAN SERVICES
March 28, 2014

SUMMARY: FUNDING RECOMMENDATIONS (in millions $)

National Institutes of Health	$32,000
National Heart, Lung & Blood Institute	$3,214
National Institute of Allergy & Infectious Disease	$4,701
National Institute of Environmental Health Sciences	$717.7
Fogarty International Center	$72.7
National Institute of Nursing Research	$151
Centers for Disease Control and Prevention	$7,800
National Institute for Occupational Safety & Health	$292.3
Asthma Programs	$28
Div. of Tuberculosis Elimination	$243
Office on Smoking and Health	$250
National Sleep Awareness Roundtable (NSART)	$1

The ATS's 15,000 members help prevent and fight respiratory disease through research, education, patient care and advocacy.

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, asthma, and critical illness.

National Institutes of Health

The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and tuberculosis. But due to eroded

funding, the success rate for NIH research grants has plummeted to below 13%, which means that more than 85% of meritorious research is not being funded. The implementation of budget sequestration in FY2013 will cut NIH by an additional $1.5 billion, which will result in the elimination of at least 1,000 grant opportunities and cuts of up to 10 percent for continuing grants. These cuts will result in the halting of vital research into diseases affecting millions around the world. **We ask the subcommittee to provide $32 billion in funding for the NIH in FY2015.**

Despite the rising lung disease burden, lung disease research is underfunded. In FY2012, lung disease research represented just 23.2% of the National Heart Lung and Blood Institute's (NHLBI) budget. Although lung disease is the third leading cause of death in the U.S., research funding for the disease is a small fraction of the money 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.

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 a 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 and occupational safety and health research and training. **The ATS recommends a funding level of $7.8 billion for the CDC in FY2015.**

COPD

COPD is the third 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. CDC estimates that

12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease. In 2010, the estimated economic cost of lung disease in the U.S. was $186 billion, including $117 billion in direct health expenditures and $69 billion in indirect morbidity and mortality costs.

The NHLBI is developing a national action plan on COPD, in coordination with the Centers for Disease Control and Prevention (CDC) to expand COPD surveillance, development of public health interventions and research on the disease and increase public awareness of the disease and we urge Congress to support it. We also urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES) and the National Health Information Survey (NHIS).

TOBACCO CONTROL

Cigarette smoking is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. The ATS is pleased that the Department of Health and Human Services has made tobacco use prevention a key priority. 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 a total funding level of $250 million for the Office of Smoking and Health in FY2015.**

ASTHMA

Asthma is a significant public health problem in the United States. Approximately 25 million Americans currently have asthma. In 2010, 3,388 Americans died as a result of asthma exacerbations. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. The disease costs our healthcare system over $50.1 billion per year. African Americans have the highest asthma

prevalence of any racial/ethnic group and the age-adjusted death rate for asthma in this population is three times the rate in whites.

We ask that the subcommittee's appropriations request for FY2015 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least $28 million.

SLEEP

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, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. **The ATS recommends a funding level of $1 million in FY15 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 1.3 million lives each year. In the U.S., every state reports cases of TB annually. Drug-resistant TB poses a particular challenge to domestic TB control due 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 present a persistent public health threat to the U.S.

The Comprehensive Tuberculosis Elimination Act (CTEA, P.L. 110-392), enacted in 2008, reauthorized programs at CDC with the goal of putting the U.S. back on the path to eliminating TB. **The ATS, recommends a funding level of $243 million in FY 2015 for CDC's Division**

of TB Elimination, as authorized under the CTEA, and encourages the NIH to expand efforts to develop new tools to reduce the rising global TB burden.

CRITICAL ILLNESS

The burden associated with the provision of care to critically ill patients is enormous, and is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. This is the approximately the same number of deaths each year due to breast cancer, colon cancer, and prostate cancer combined. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a priority, and the NIH should be encouraged and funded to coordinate investigation in this area in order to meet this growing national imperative.

FOGARTY INTERNATIONAL CENTER

The Fogarty International Center (FIC) 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 professionals in TB treatment and research. **The ATS recommends Congress provide $72.8 million for FIC in FY2015, to allow expansion of the TB training grant program from a supplemental grant to an open competition grant.**

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

As Congress considers funding priorities for Fiscal Year 2015, the ATS urges the subcommittee to provide at least level funding for the National Institute for Occupational Safety and Health (NIOSH). NIOSH, within the Centers for Disease Control and Prevention (CDC), is the primary federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury.

Statement

Of

The National Association of Chain Drug Stores

For

U.S. House of Representatives

Committee on Appropriations

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

On

Fiscal Year 2015 Budget

National Association of Chain Drug Stores (NACDS)
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The National Association of Chain Drug Stores (NACDS) thanks the Members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies for the opportunity to submit the following statement for the record regarding pharmacy-related provisions contained within the Fiscal Year 2015 Department of Health and Human Services (HHS) Budget. NACDS and the chain pharmacy industry are committed to partnering with Congress, HHS, patients, and other healthcare providers to improve the quality and affordability of healthcare services.

NACDS represents traditional drug stores and supermarkets and mass merchants with pharmacies. Chains operate more than 40,000 pharmacies, and NACDS' 125 chain member companies include regional chains, with a minimum of four stores, and national companies. Chains employ more than 3.8 million individuals, including 175,000 pharmacists. They fill over 2.7 billion prescriptions yearly, and help patients use medicines correctly and safely, while offering innovative services that improve patient health and healthcare affordability. NACDS members also include more than 800 supplier partners and nearly 40 international members representing 13 countries. For more information, visit www.NACDS.org.

As the face of neighborhood healthcare, community pharmacies and pharmacists provide access to prescription medications and over-the-counter products, as well as cost-effective health services such as immunizations and disease screenings. Through personal interactions with patients, face-to-face consultations and convenient access to preventive care services, local pharmacists are helping to shape the healthcare delivery system of tomorrow—in partnership with doctors, nurses and others.

In recent years, retail community pharmacies have played an increasingly important role in providing patient care, including medication therapy management (MTM) and expanded immunization services. Moreover, policymakers have begun to recognize the vital role that local pharmacists can play in improving medication adherence. The role of appropriate medication use in lowering healthcare costs was recently acknowledged by the Congressional Budget Office (CBO). The CBO revised its methodology for scoring proposals related to Medicare Part D and found that for each one percent increase in the number of prescriptions filled by beneficiaries there is a corresponding decrease in overall Medicare spending. When projected to the entire population, this translates into a savings of $1.7 billion in overall healthcare costs, or a savings of $5.76 for every person in the U.S. for every one percent increase in the number of prescriptions filled.

Congress has recognized the importance of pharmacist-provided services such as MTM by including it as a required offering in the Medicare Part D program. The experiences of Part D beneficiaries, as well as public and private studies, have confirmed the effectiveness of pharmacist-provided MTM. A 2013 CMS report found that Part D MTM programs consistently and substantially improved medication adherence and quality of prescribing for evidence-based medications for beneficiaries with congestive heart failure, COPD, and diabetes. The study also found significant reductions in hospital costs, particularly when a comprehensive medication review (CMR) was utilized. This included savings of nearly $400 to $525 in overall hospitalization costs for beneficiaries with diabetes and congestive heart failure. The report also found that MTM can lead to reduced costs in the Part D program as well; showing that the best performing plan reduced Part D costs for diabetes patients by an average of $45 per patient.

How and where MTM services are provided also impact its effectiveness. A study published in the January 2012 edition of *Health Affairs* identified the key role of retail pharmacies in providing MTM services. The study found that a pharmacy-based intervention program increased adherence for patients with diabetes and that the benefits were greater for those who received counseling in a retail, face-to-face setting as opposed to a phone call from a mail-order pharmacist. The study suggested that interventions such as in-person, face-to-face interaction between the retail pharmacist and the patient contributed to improved adherence behavior with a return on investment of 3 to 1.

Since pharmacists have the proven ability to provide services that lead to better clinical outcomes and lower healthcare costs, we urge the implementation of budget proposals that allow all healthcare providers, including retail pharmacists, to practice to their maximum capabilities, working in partnership to provide accessible, high quality care to patients.

NACDS appreciates HHS's proposed goals to reduce healthcare costs and produce a more efficient healthcare system; however, we have concerns with some proposals contained in the FY2015 HHS Budget. HHS has proposed excluding brand and authorized generic drugs from the calculation of average manufacture price (AMP), thereby calculating Medicaid Federal Upper Limits (FULs) based only on generic drug prices. While the goal of this provision may be to decrease Medicaid costs, we believe it may in fact reduce access to prescription drugs and pharmacy services for Medicaid patients, resulting in increased overall healthcare expenditures.

Given that AMP has never been used as a basis for pharmacy reimbursement, and that AMP-based FULs remain in draft form, we believe the FY2015 budget provisions changing the

calculation of FULs are premature. In fact, based on NACDS' most recent analysis, approximately 35 percent of the draft FULs are below National Average Drug Acquisition Cost (NADAC). This analysis confirms that additional efforts by the Centers for Medicare and Medicaid Services (CMS) are necessary to ensure that pharmacies are not reimbursed below their costs using the reimbursement formula created by the Affordable Care Act. We urge CMS to utilize the rulemaking process to implement the Medicaid pharmacy provisions in a manner consistent with Congressional intent, rather than pursuing policies that would further cut pharmacy reimbursement.

The FY2015 HHS Budget includes a proposal to limit Medicaid reimbursement of durable medical equipment (DME) to the rates paid by Medicare. Implementing a blanket proposal to reduce payment for Medicaid DME has the potential to disrupt access to DME and produce poorer health outcomes. This is particularly true in the case of diabetes testing supplies (DTS). Last year, CMS established a new Medicare single payment of $10.41 for DTS. This amount drastically decreased Medicare reimbursement by an average of 72 percent for retail pharmacies. The current reimbursement amount barely covers a pharmacy's costs-of-goods plus dispensing and counseling for these products and services. Reducing Medicaid reimbursement for DTS to match the Medicare rate could similarly produce hardships for Medicaid beneficiaries in terms of reducing access to needed supplies and threatening the health of an already fragile population. NACDS urges CMS to refrain from making any changes to Medicaid reimbursement for DTS.

The FY2015 budget also includes several provisions to increase the utilization of generic drugs. NACDS applauds the inclusion of these important provisions, which would

encourage the use of generic medications by Medicare Low Income Subsidy beneficiaries, and promote generic competition for biologics. Increasing generic utilization is one of the most effective ways of controlling prescription drug costs, and the generic dispensing rate of retail pharmacies—80 percent—is higher than any other practice setting.

Finally, the FY2015 HHS Budget includes a number of proposals to cut waste, fraud and abuse in the Medicare and Medicaid programs, including the ability to suspend coverage and payment for questionable Part D prescriptions. NACDS applauds HHS for working to ensure that such activity does not exist in these federal programs. However, NACDS urges HHS to move forward in a cautious manner which does not disrupt beneficiary access or jeopardize beneficiary health. This can be done by ensuring that overly-burdensome requirements are not placed on providers to the point that it interferes with the ability to treat and care for patients.

NACDS thanks the Subcommittee for consideration of our comments. We look forward to working with policymakers and stakeholders on these important issues.

Name: Terry Johnson

Title: Parent & Guardian of a 32 year old Adult with Intellectual/Developmental Disabilities (Autism)

Institutional Affiliation: Friends & Families of Care Facility Residents (FF/CFR) and Jonesboro Human Development Center Parent Association

March 25, 2014

To: House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Re: 2015 Budget – Department of Health and Human Services

Dear Appropriations Subcommittee Members:

Thank you for this opportunity to submit Testimony for the Record regarding the 2015 Budget for the Department of Health and Human Services and the elimination of funding of harmful programs under this budget.

I am the father and guardian of an adult son, age 32, whose home is a state-operated, Medicaid-certified congregate care facility in Jonesboro, Arkansas. Danny has been developmentally disabled since age 2. His cognitive level of understanding is approximately 4 years old. Danny lived in our home until he was 19 years old, and then his needs seemed to change. He needed more activity and structure, similar to what high school had provided. We tried 4 Medicaid Waiver Organizations over the next 10 years. BOST, Arkansas Support Network, Lifestyles, and Pathfinder.

My testimony today is regarding the Department of Health and Human Services 2015 Budget. A partial list of federal programs included in the DHHS appropriations which I find offending are:

1) National Council on Disability (NCD);
2) Administration on Intellectual and Developmental Disabilities (AIDD); and
3) DD Act Programs, which include:
   - State Developmental Disabilities Councils;
   - Protection & Advocacy Organizations; and
   - University Centers of Excellence on Developmental Disabilities

These federally funded programs' actions promote public policies that are dangerous to individuals like my son! They publically and actively use their funds to promote the down-sizing and closure of facilities that serve the most vulnerable individuals our society has to care for. These "facilities" are "home" to so many people with diverse special needs! My son loves his home at the Jonesboro HDC! He is very well cared for, and still has the opportunity to participate in his local community; moreso by far than ever with the Waiver groups ~~these~~ whose aggressive federally funded programs try to force deinstitutionalization of people with severe, profound, and extreme forms of intellectual and developmental disabilities!

Our state's Protection & Advocacy Organization (Disability Rights Center) has publically asked for the closure of our Intermediate Care Facilities (ICFs) that have historically proven to be very good and sound programs. Just this month the DRC has asked our state <u>not</u> to spend any more money to support the vital life sustaining centers (ICFs). Also, DRC has filed class action law suits in the past, including our loved ones with profound intellectual disabilities as part of those law suits and without our knowledge! This should be illegal in the first place!! There needs to be a law against it!! The courts have already ruled that the legal guardian is the one to

make decisions when it comes to those they represent. However, we are not given the chance to "opt out" of those lawsuits on behalf of our loved ones! This is just an example of one of the programs and the harmful activities they produce. We have many more examples!

The nation's service system for individuals with severe cognitive developmental disabilities has been weakened by the aggressive deinstitutionalization activities of the programs mentioned above.

I would ask that you consider the following:

- ***cease giving federal funds to programs that undermine, weaken and eliminate licensed Medicaid - certified residential facilities for persons with developmental disabilities;***
- ***cease giving federal funds to support the deinstitutionalization activities of these programs; and***
- ***cease providing federal funds (grants) to organizations which have worked and are working to eliminate congregate care facilities for persons with developmental disabilities.***

Thank you for the opportunity to comment.

Respectfully submitted,

Terry Johnson

cc: Arkansas Congressional Delegation

Families & Friends of Care Facility Residents

National Parent-Guardian Network

National Children's Alliance
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Washington DC 20002
202 548 0090 telephone
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WRITTEN TESTIMONY of

TERESA HUIZAR, EXECUTIVE DIRECTO

NATIONAL CHILDREN'S ALLIANCE

For the

US HOUSE OF REPRESENTATIVES

COMMITTEE ON APPROPRIATIONS

SUB-COMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,

EDUCATION AND RELATED AGENCIES

MARCH 28, 2014

Chairman Kingston, Ranking Member DeLauro and Members of the Subcommittee:

Thank you for the opportunity to provide testimony regarding the funding priorities of the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies.

National Children's Alliance is the national association and accrediting body for almost 800 Children's Advocacy Centers throughout the US. We empower local communities to respond to child abuse by providing grants for the start-up and development of Children's Advocacy Centers which coordinate a multidisciplinary team for the investigation, prosecution, and treatment of child abuse. Funded in part through federal funds, these Children's Advocacy Centers served almost 300,000 child victims of abuse throughout the US in 2013; a majority of whom were victims of sexual abuse and child sexual exploitation and trafficking. In addition, Children's Advocacy Centers provided child abuse prevention education to more than 1.2 million individuals in the US alone. As you begin drafting your Subcommittee's Fiscal Year 2015 Appropriations bill, we encourage the Subcommittee's support for increased domestic child sex trafficking funding, specifically to help these victims heal.

Child Sexual Abuse and Child Sex Trafficking

Children of every gender, age, ethnicity, socioeconomic status, and family structure are at risk for sexual abuse and exploitation. Child sexual abuse and exploitation is a crime perpetuated by silence and secrecy. Isolation, whether within a family or by community, adds significant risk for sexual abuse. Understanding the scope of the problem also requires understanding that child sexual abuse exists on a continuum of deviant and harmful behavior by the perpetrator that begins on one end with secretive and furtive victimization, may move into amateur or professional photo-documentation of that abuse primarily for the sexual gratification of the offender, or may move toward commercialization or public sharing of those images with other offenders, and on the far end of that continuum may include prostituting or trafficking the child. Sadly, many children who are abused at home later become youth who are trafficked on the streets by others. And, of course, a child/youth may experience one, all, or some combination of these forms of child sexual abuse.

Responding to Child Abuse, Trafficking and the Role of Children's Advocacy Centers

Children's Advocacy Centers not only play a key role in the investigation and prosecution of child abuse cases, but more importantly, in the healing of victims. Children's Advocacy Centers are child-friendly facilities in which a multidisciplinary team comprised of law enforcement, child protective services, prosecutors, victim advocates, medical practitioners, and mental health professionals convenes and coordinates its efforts to investigate and prosecute child abuse cases while protecting children and providing needed treatment to victims. Across the United States, there are almost 800 Children's Advocacy Centers, which together served almost 300,000 child victims of abuse in 2013 alone.

The majority of these Children's Advocacy Centers were founded after the passage of the Victims of Child Abuse Act in 1990; which was an important part of Congress' efforts to improve not only the investigation and prosecution of child abuse, but also in the treatment of child abuse victims. Monies appropriated by Congress, each year since 1992, have improved the response within existing Centers, while aiding the development of new Children's Advocacy Centers in areas previously underserved. This much appreciated modest federal investment has been used to leverage state funding, private foundations, and local community donors.

In addition, Children's Advocacy Centers have trained forensic interviewers available who understand how to question children and teens in a culturally and developmentally appropriate way. Many CACs, particularly urban ones, are already providing such services to commercially sexually exploited youth. And, those that are not could do so with a small federal investment in training to serve this specific population. National Children's Alliance has actively encouraged CACs to provide services to commercially sexually exploited youth and has funded grants in this area to local Children's Advocacy Centers for the past few years.

Furthermore, to encourage the use of CACs by federal law enforcement agencies, NCA has been working with the FBI to overlay the service coverage of Children's Advocacy Centers with locations of the FBI's Innocence Lost Task Forces so that standard operating procedures may be developed for their ongoing use. While individual CACs have been, and continue to be used by

FBI agents as they work these difficult cases, our goal is to ensure that each Task Force has ready access, and a standard operating procedure with at least one NCA accredited CAC, to ensure smooth operations and provide the best possible and immediate care for these children/youth. All CACs can and should be used in this way as a regular part of the response repertoire.

Services for Child Sexual Abuse Victims

While child abuse and exploitation investigations are important to the safety of victims and the accountability of offenders, we must also help victims learn to cope with the trauma they have endured. Child sexual abuse and exploitation have well-documented life-long effects. Victims of child sexual abuse are more likely than their non-abused counterparts to become pregnant as teens, to drop out of high school, to abuse substances, to engage in self-destructive and risk-taking behavior, and to experience anxiety and depression. As adults, these individuals have increased morbidity and mortality, suffering from a host of physical and mental ailments at higher rates than their non-abused peers.[1] Moreover, their own children are more likely to suffer sexual abuse during the course of their lifetimes than other children. This is truly the saddest possible cycle of abuse.[2]

This host of maladies is the result of the trauma caused by abuse. Child abuse and exploitation victims experience rates of trauma symptoms (hyperarousal, fear, sleep disturbances, anxiety, depression) at rates verging on those experienced by war veterans. Fortunately, much has been learned over the past 15 years about successfully treating trauma in children. Every child/youth who has been the victim of abuse deserves to be assessed to see if they would benefit from mental health treatment, and if so, to have it provided to them promptly.

Abused children served within Children's Advocacy Centers have access to such trauma-focused, evidence-supported mental health treatment. In addition, Children's Advocacy Centers, through Commercially Sexually Exploited Children (CSEC) grants awarded by National Children's Alliance, focus on the needs of child sex trafficking victims by designing programs that support a coordinated and expanded response to effectively identify and treat trafficking

[1] Dube S.R., Anda R.F., Whitfield C.L., Brown D.W., Felitti V.J., Dong M., Giles W.H. (2005). Long-term consequences of childhood sexual abuse by gender of victim. American Journal of Preventive Medicine, 28 (5), pp. 430-438.
[2] Penelope K. Trickett, Jennie G. Noll and Frank W. Putnam (2011). The impact of sexual abuse on female development: Lessons from a multigenerational, longitudinal research study. Development and Psychopathology, 23 , pp 453-476 doi:10.1017/S0954579411000174

victims. For the over 286,000 children served within Children's Advocacy Centers last year, including the child sex trafficking victims, there is no doubt that the care they received was improved, and the suffering they experienced was reduced, for having had access to such targeted treatment.

In Summary

Child sexual abuse is far too common experience for America's children. And, with the number of child sex trafficking cases skyrocketing, the ability of Children's Advocacy Centers to serve as first responders is critical. Therefore, we encourage your support for increased domestic child sex trafficking funding, specifically to help these victims heal in the Subcommittee's Fiscal Year 2015 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. Thank you.

Testimony of The Society for Healthcare Epidemiology of America (SHEA)
and the Association for Professionals in Infection Control and Epidemiology (APIC)
to the U.S. House of Representatives Appropriations Subcommittee on
Labor, Health and Human Services, Education and Related Agencies on
Fiscal Year 2015 Appropriations for the U.S. Department of Health and Human Services (HHS)
March 28, 2014

The Society for Healthcare Epidemiology of America (SHEA) and the Association for Professionals in Infection Control and Epidemiology (APIC) thank you for this opportunity to submit testimony on federal efforts to detect dangerous infectious diseases, protect the American public from preventable healthcare-associated infections (HAIs) and address the rapidly growing threat of antibiotic resistance (AR). We ask that you support the following programs: First, under the Centers for Disease Control and Prevention National Center for Emerging and Zoonotic Infectious Diseases: $250 million for Core Infectious Diseases including $30 million for the new Detect and Protect Against Antibiotic Resistance (AR) Initiative, $32 million for the National Healthcare Safety Network (NHSN), and $30 million for the Advanced Molecular Detection (AMD) Initiative. Additionally, we request $34 million for HAI research activity conducted by the Agency for Healthcare Research and Quality (AHRQ) and $4.58 billion for the National Institutes of Health/National Institute of Allergy and Infectious Diseases (NIAID).

HAIs are among the leading causes of preventable death in the United States. In hospitals alone, CDC estimates that one in 25 patients has an HAI, totaling approximately 722,000 infections in 2011. According to the CDC, every day, more than 200 Americans with HAIs will die during their hospital stay. Further, AR is one of the most critical public health and patient safety threats facing us today, causing an estimated two million illnesses and approximately 23,000 deaths annually. It is estimated that as much as half of antibiotic prescribing in hospitals is not necessary. Antibiotics, created to save lives, are now contributing to patient's deaths by promoting the emergence of highly resistant bacteria and leading to deadly adverse events.

Centers for Disease Control and Prevention (CDC)

We urge you to support the CDC Coalition's request for $7.8 billion in FY 2015 for the CDC's "core programs." We are concerned that the President's FY 2015 budget proposal would reduce the CDC's budget authority by $243 million when compared with FY 2014. This total is, in fact, lower than 2003 levels. We urge Congress to prioritize funding for the activities and programs supported by CDC that are essential to protect the health of the American people and reduce healthcare costs.

We especially want to highlight our support for the $30 million in the President's budget for the Detect and Protect Against Antibiotic Resistance (AR) Initiative. This initiative will establish a robust network of five regional labs that will detect the deadliest AR threats and protect patients and communities through the rapid identification of outbreaks, saving lives and reducing healthcare costs. It will prioritize healthcare prevention collaboratives focused on improving antibiotic use and preventing deadly infections caused by *Clostridium difficile (C. diff)*, carbapenem-resistant Enterobacteriaceae (CRE), *Pseudomonas*, and methicillin-resistant *Staphylococcus aureus (MRSA)*. Most importantly, the initiative will invest in direct action by implementing proven evidence-based interventions that reduce the emergence and spread of AR pathogens and improve antibiotic use. It is critical that Congress prioritize this rapidly growing threat to public health and patient safety in our nation and around the world. Moreover, we strongly support CDC's focus on the implementation of antimicrobial stewardship programs in all healthcare settings.

We urge you to support the $32 million in the President's budget for the CDC's National Healthcare Safety Network (NHSN). The President's request represents a $14 million increase over the FY 2014 enacted level for the NHSN to extend HAI prevention efforts to more than 3,000 ambulatory surgery centers and other non-hospital settings. This will enable CDC to conduct applied research on interventions for infection prevention and continue to provide data for national HAI elimination and targeted HAI prevention intervention. This funding level will also allow for the extension and implementation of the NHSN Antimicrobial Use and Resistance Components to enable rapid detection of highly resistant pathogens and

track antibiotic use in healthcare settings.

The NHSN serves as the foundation for the development of innovative, evidence-based HAI prevention strategies through high-quality monitoring of HAI prevalence as well as antibiotic usage in the US. It is a critical tool used by healthcare facilities to monitor and prevent HAIs. The NHSN provides medical facilities, states, regions, and the nation with data collection and reporting capabilities needed to comply with state and federal public reporting mandates, including the Centers for Medicare & Medicaid Services' Value-Based Purchasing Program. Consistent, scientifically sound and validated data are necessary to be reported at the state and federal levels to ensure that accurate data are available to evaluate progress related to the HHS National Action Plan to Prevent HAIs as well as to support transparency to the public, allowing for fair comparisons between facilities.

By August 2013, over 12,400 healthcare facilities, including nearly all US hospitals, participated in NHSN for quality improvement. The number of acute care hospitals reporting multi-drug resistant organisms (such as *C.diff* and MRSA) through NHSN more than doubled to 4,000 in FY 2013. Since 2008, the cumulative impact of CDC data systems, guidelines and programs has contributed to significant reductions of HAIs in healthcare settings, including a 44% reduction in central line-associated bloodstream infections, a 31% reduction in healthcare-associated invasive MRSA infections, and a 20% reduction in surgical site infections.

We strongly support the CDC Prevention Epicenters Program. Funded through the NHSN, this program is a collaboration between CDC and academic medical centers that conduct innovative infection control and prevention research to address important scientific questions regarding the prevention of HAIs, antibiotic resistance and other adverse healthcare events. The Epicenters Program has provided a unique forum in which academic leaders in healthcare epidemiology can partner directly with each other and with CDC subject matter experts. The resultant emphasis on multicenter collaborative research projects, through which investigators work together as a group, allows for research that in many cases, would not have been

possible for a single academic center. Going forward, the Prevention Epicenters will continue to address gaps and pilot innovative ways to prevent HAIs and antimicrobial resistance.

We urge your continued support of the President's $30 million request for the Advanced Molecular Detection (AMD) Initiative in bioinformatics and genomics, which allows CDC to more quickly determine where emerging diseases come from, whether microbes are resistant, and how microbes are moving through a population. This Initiative is critical because it strengthens CDC's epidemiologic and laboratory expertise to effectively guide public health action.

We strongly support the critical work conducted through the Emerging Infections Program (EIP), which engages a network of state health departments and their academic medical center partners to help answer important questions about emerging HAI threats, advanced infection tracking methods and antibiotic resistance in the U.S.

Agency for Healthcare Research and Quality

We request your support of the proposed investment of $34 million for AHRQ's HAI research activity, the level of enacted support in FY 2014. Building on the successes of FY 2013 and 2014, these funds will support a portfolio of grant- and contract-funded projects seeking to advance our knowledge about effective approaches to reducing HAIs while promoting the implementation of proven methods for preventing HAIs. These grants ($13.9 million) and contracts ($20.1 million) will investigate methods of controlling HAIs in diverse healthcare settings and will address the major types of HAIs. In addition, contracts funded by the HAI budget will accelerate the nationwide implementation of the Comprehensive Unit-based Safety Program (CUSP). To date, widespread adoption of this evidence-based checklist of safety practices to over 1,000 intensive care units has reduced the incidence of central line-associated bloodstream infections (CLABSIs) by 41%. Our organizations are pleased to participate in the *On the CUSP: Stop CAUTI* initiative, which aims to reduce mean rates of CAUTI in U.S. hospitals by 25 percent by working with state organizations and hospitals across the country to implement the CUSP and catheter-associated urinary tract infection (CAUTI)

reduction practices in hospital units. In spite of notable progress, there remains work to be done toward the goal of HAI elimination.

National Institutes of Health (NIH)/National Institute of Allergy and Infectious Diseases (NIAID)

Within NIH, we believe that the **National Institute of Allergy and Infectious Diseases (NIAID) should be funded at least at the $4.58 billion requested by the Administration in the FY 2014 budget request.** Nearly flat-funding NIAID limits investment in new research and serves as a disincentive for young people to pursue infectious disease research careers so critical to the discovery of new therapies, new diagnostic approaches, and new preventive strategies.

In 2013, the NIAID began funding a new clinical trials network focused on antibiotic-resistant bacterial infections. With sufficient funding, the new research network/infrastructure will conduct studies to address antibiotic resistance as well as begin to answer questions that will help fill the nearly empty antibiotic research and development pipeline. Severe economic disincentives have caused a mass exodus of private companies from the antibiotics market, making federally funded research in this area more critical than ever. We applaud NIAID's initiative in launching the new network. We recommend increased investment in this area.

We thank you for the opportunity to submit testimony and greatly appreciate your leadership in the effort to eliminate preventable HAIs and combat antibiotic resistance.

Please forward questions to: Melanie Young, Policy & Strategic Initiatives Director, SHEA, myoung@shea-online.org
Lisa Tomlinson, Senior Director, Government Affairs, APIC, ltomlinson@apic.org

About SHEA: SHEA is a professional society representing more than 2,000 physicians and other healthcare professionals globally who have expertise in and passion for healthcare epidemiology and infection prevention. SHEA's mission is to prevent and control healthcare-associated infections and advance the field of healthcare epidemiology. The society promotes science and research, develops expert guidelines and guidance for healthcare workers, provides high-quality education, promotes antimicrobial stewardship, encourages transparency in public reporting related to HAIs, works to ensure a safe healthcare environment, and facilitates the exchange of knowledge.

About APIC: APIC's mission is dedicated to creating a safer world through prevention of infection. The association's more than 15,000 members direct and maintain infection prevention programs that prevent suffering, save lives and contribute to cost savings for hospitals and other healthcare facilities. APIC advances its mission through patient safety, implementation science, competencies and certification, advocacy, and data standardization.

Testimony of the Tri-Council for Nursing Regarding Fiscal Year (FY) 2015 Appropriations for the Title VIII Nursing Workforce Development Programs

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

Department of Health and Human Services

March 28, 2014

Submitted on behalf of the Tri-Council for Nursing by Suzanne Miyamoto, Director of Government Affairs and Health Policy, American Association of Colleges of Nursing

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 **$251 million for the Nursing Workforce Development programs authorized under Title VIII of the *Public Health Service Act* (42 U.S.C. 296 et seq.) and administered by the Health Resources and Services Administration in FY 2015**.

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. The members of these respective organizations are acutely aware of the demand for nursing services due to a growing aging population, an increased focus on preventative care, and skyrocketing rates of individuals with multiple chronic conditions. In fact, according to the U.S. Bureau of Labor Statistics (BLS) *Employment Projections for 2012-2022* the profession of registered nurses (RN) will grow 19 percent for the 10-year timeframe between 2012 and 2022. The number of job openings due to demand for RNs and replacements brings the total of RNs needed to 1.053 million by 2022. Replacements in the nursing workforce represent the impending wave of RN retirements. A 2013 HRSA report *The U.S. Nursing Workforce: Trends in Supply and Education* indicates that over the next 10 to 15 years, the nearly one million RNs over age 50 (comprising approximately one-third of the current workforce), will reach retirement age.

Moreover, the acute nurse faculty shortage is one significant reason why schools of nursing across the country turn away tens of thousands of qualified applications each year. The demand for nurses and the faculty who educate them is a serious impediment to improving the nation's healthcare needs. Nurses continue to be the largest group of health care providers whose services are directly linked to quality and cost-effectiveness. The Tri-Council is grateful to the Subcommittee for your past commitment to Title VIII funding and respectfully asks that you continue to make the long-term investment that will build the nursing workforce necessary to deliver the quality, affordable care envisioned in health reform.

A Proven Solution: Nursing Workforce Development Programs

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs since 1964. Over these past 50 years, the original programs, newly added and expanded programs have addressed all aspects of supporting the workforce – education, practice, retention, and recruitment. They have bolstered nursing education at all levels – from entry-level preparation through graduate study – and have provided support for institutions that educate nurses for practice in rural and medically underserved communities. A description of the Title VIII programs and their impact are included below.

Advanced Nursing Education (ANE) Programs (Sec. 811) fund a number of grant activities – including several traineeships – that aim to increase the size and quality of the advanced nursing workforce. Supporting the preparation of RNs in master's and doctoral nursing programs, the ANE grants help prepare our nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, nurses in executive practice, public health

nurses, and other nursing specialists requiring advanced nursing education. In FY 2012, these grants supported the education of 15,986 students. Under the ANE program are two critical traineeship programs that are particularly relevant as the demand for primary and acute care services rise.

AEN Traineeships assist graduate nursing students by providing full or partial reimbursement for the costs of tuition, books, program fees, and reasonable living expenses. Funding for the AEN Traineeships supports the education of future nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and other nurse specialists requiring advanced education.

Nurse Anesthetist Traineeships (NAT) support the education of students in nurse anesthetist programs. In some states, certified registered nurse anesthetists are the sole anesthesia providers in almost 100% of rural hospitals. In FY 2012, the AEN Traineeship and the NAT supported 5,545 nursing students.

Nursing Workforce Diversity (NWD) Grants (Sec. 821) prepare students from disadvantaged backgrounds to become nurses, producing a more diverse nursing workforce. This outcome will help meet the increasing need for culturally aligned, quality health care for the nation's rapidly diversifying population and help close the gap in health disparities. This program awards grants and contract opportunities to schools of nursing for a variety of clinical training facilities to address nursing educational needs for not only disadvantaged students but also racial and ethnic minorities underrepresented in the nursing profession. In FY 2012, the program supported 12,077 students.

Nurse Education, Practice, Quality and Retention (NEPQR) Grants (Sec. 831, and Sec. 831 A) help schools of nursing, academic health centers, nurse managed health centers, state and local governments to strengthen nursing education programs thereby increasing the size and quality of the nursing workforce. The purposes of the NEPQR are broad and flexible, allowing the program to address emerging needs in nursing workforce development. For example, projects to develop and

disseminate collaborative practice models that incorporate the full range of health care workers in team-based care are of certain interest. NEPQR supports infrastructure development to enhance the coordination and capacity building of interprofessional practice and education among health professions across the United States, and particularly in medically underserved areas. For other interests, a number of grant activities have been funded to support several legislative purposes such as expanding the size of academic programs that are able to confer a baccalaureate degree of science in nursing (BSN); recruiting and educating individuals as qualified personal and home care aides in occupational shortage and/or high demand areas; training qualified nursing assistants and home health aides to meet the growing health care needs of the aging population; and/or supporting nurse managed health clinics that serve as primary care access points in areas where primary care providers are in short supply.

NURSE Corps ***(formerly known as the Nursing Education Loan Repayment and Scholarship Program)*** (Sec. 846, Title VIII, PHSA) provides monies to students by paying up to 85 percent of a student's loan in return for at least three years of service in a designated health shortage area or in an accredited school of nursing. The NURSE Corps Loan Repayment Program (LRP) is a financial incentive program under which individual RNs and advanced practice RNs (APRNs) enter into a contractual agreement with the federal government to work full-time in a health care facility with a critical shortage of nurses, in return for repayment of qualifying nursing educational loans. In FY 2013, the Nursing Education Loan Repayment Program supported 1,446 nurses working in these facilities. However, given the current climate, the HRSA 2015 Congressional Budget Justification anticipates that they can only support 1,296 in FY 2014.

Nurse Faculty Loan Program (NFLP) (Sec. 846 A, Title VIII, PHSA) increases the number of qualified nurse faculty by creating a student loan fund within individual schools of nursing and supporting individual students. Students 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 2012, these grants supported the education of 2,259 future nurse educators.

Comprehensive Geriatric Education Program (CGEP) Grants (Sec. 855, Title VIII, PHSA) provide support to nursing students specializing in care for the elderly. These grants may be used to educate RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, prepare faculty members, and provide continuing education. They may also fund traineeships for individuals who are preparing for advanced education nursing degrees in geriatric nursing, long-term care, gero-psychiatric nursing or other nursing areas that specialize in the care of the elderly population. In FY 2012, there were 11,600 trainees supported by these grants.

Our nation is faced with a growing health care crisis that must be addressed on many fronts. Nurses are an important part of the solution to the crisis of cost, burden of disease, and access to quality care. To meet this challenge, funding of proven federal programs such as Title VIII will help ease the demand for RNs. The Tri-Council respectfully requests your support of $251 million for the Title VIII Nursing Workforce Development Programs in FY 2015.

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Statement of the National Health Service Corps (NHSC) Stakeholders

on FY 2015 funding for the NHSC

submitted, March 28, 2014, for the record to the

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

Through more than 40 national organizations, the NHSC Stakeholders represent the multiple health professionals, institutions, and underserved areas/patients that benefit from the NHSC's scholarship and loan repayment awards. The NHSC Stakeholder associations urge a sustained, long-term investment in the NHSC of both mandatory and discretionary funding to help care for our nation's most vulnerable populations.

The NHSC offers scholarship and loan repayment awards to primary care health professionals in exchange for service in a federally designated Health Professional Shortage Area (HPSA). Additionally, the NHSC matches funding for State-based loan repayment programs with similar missions. In FY 2012, the NHSC created the Students to Service (S2S) Loan Repayment Program, which provides a primary care recruitment incentive as medical students choose their specialty and begin their careers in residency training.

As the nation faces multiple health professions workforce shortages, expanding the NHSC's reach is critical to improving the distribution of our national health care workforce. The NHSC Stakeholders appreciate the overall funding level of $810 million for the NHSC proposed in the president's budget for FY 2015. Furthermore, the NHSC Stakeholders support the proposed

5-year mandatory funding investment ($710 million for each of FYs 2016-2020[1]). A funding approach that includes both mandatory and discretionary funding ensures annual flexibility with out-year stability. As such, we encourage congressional authorizers and appropriators to work together before current mandatory funding for the NHSC expires at the end of FY 2015.

The NHSC is widely recognized—both in Washington and in the underserved areas it helps—as a success on many fronts. The simple, yet historically effective design of the program:

- improves access to health care for the growing numbers of rural and urban underserved Americans;
- increases state investments in recruiting health professionals;
- 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.

In spite of the NHSC's success, demand for health professionals across the country continues to grow. With a field strength of 8,899 in FY 2013, the NHSC fell far short of fulfilling the health care needs of all federally designated shortage areas. Even the potential 15,000+ field strength envisioned in the president's budget will likely leave a number of underserved areas still lacking access to primary care.

[1] Fiscal Year 2015 HRSA Justification of Estimates for Appropriations Committees (HHS, March 2014)

As of January 1, 2014, the Health Resources and Service Administration (HRSA) estimates that 17,653 additional practioners are required to eliminate all current primary care, dental, and mental HPSAs.[2] A more conservative ratio of 1 primary care physician to 2,000 population boosts this need to 25,700 additional practioners to address current HPSAs.

In more tangible terms, the current NHSC practitioner deficit results in 59.4 million unserved primary care patients, 46.7 million unserved dental patients, and 94.9 million unserved mental health patients living within federally designated underserved areas spread across every state.

Thank you for the opportunity to present this funding request. We look forward to working with the House Appropriations Committee (along with its Senate and authorizing committee counterparts) to help ensure a sustained, long-term investment in the NHSC.

Should you have any questions, please contact Matthew Shick at <mshick@aamc.org> or 202-862-6116.

[2] Designated Health Professional Shortage Areas Statistics: As of January 1, 2014 (Bureau of Clinician Recruitment and Service, HRSA, HHS March 2014) http://datawarehouse.hrsa.gov/topics/shortageAreas.aspx

Clifford A. Hudis, MD, FACP

President
American Society of Clinical Oncology

Testimony for the Record 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 Cancer Institute and the National Institutes of Health for FY 2015

March 28, 2014

The American Society of Clinical Oncology (ASCO), the world's leading professional organization representing nearly 35,000 physicians and other professionals who treat people with cancer, appreciates this opportunity to provide the following recommendations for Fiscal Year 2015 (FY 2015) funding:

- National Institutes of Health (NIH): $32 billion
- National Cancer Institute (NCI): $5.26 billion

ASCO's members set the standard for cancer care world-wide and lead the way in carrying out translational and clinical research aimed at improving the screening, prevention, diagnosis and treatment of cancer. ASCO advocates for policies that provide access to high-quality care for all patients with cancer. ASCO's efforts are also directed toward supporting oncology clinical and translational research that is critical to improving the lives of our citizens and that can inform cancer services for people worldwide.

Cancer's Growing Footprint and the Importance of Federal Cancer Research

According to ASCO's *State of Cancer Care in America* report (http://www.asco.org/practice-research/cancer-care-america) released this month, cancer will surpass heart disease as the leading cause of death in the United States over the next 16 years. While cancer deaths in the United States (US) are declining for all populations, the number of new cancer cases is expected to increase nearly 45% by 2030, from 1.6 million cases to 2.3 million cases annually. The leading overall risk factor for cancer is aging and these numbers reflect overall progress in healthcare, enabling more Americans to live longer.

While we have made great strides in cancer treatment, now is not the time to cut back as cancer impacts more and more Americans. We now have more cancer survivors alive today than at any point in our history and understand more about the diseases that make up cancer than ever before. This is largely because of federal investment in cancer research, but we will not be able to harness the opportunities this new knowledge provides without further investment. Adjusting for inflation, funding for the NIH is down 23% since 2003. In addition, the NCI has become a

smaller share of NIH's total budget. If NCI was funded as the same percentage of overall NIH spending that it was in 2003, it would mean an additional $350 million for cancer research.

ASCO thanks the subcommittee for its past commitment to cancer research through the appropriations process and appreciates the unique effort made by the subcommittee in this challenging budget environment. We recognize the challenging fiscal environment faced by this subcommittee, but caution that the current path of investment in cancer research will be devastating to attempts to find future cures. ASCO calls on this subcommittee to renew the commitment to clinical cancer research – without which our basic science findings would never help improve the lives of patients.

While we appreciate the bipartisan efforts that led to a brief reprieve from sequester in FY 2015, the lasting effects of these draconian cuts, exacerbated by years of stagnant funding, will be felt for decades to come if the trend is not reversed. ASCO released a survey (http://www.asco.org/press-center/asco-survey-underscores-%E2%80%9Cdevastating%E2%80%9D-impact-stagnant-funding-cancer-research) of its members in September 2013 that showed the profound impact of sequester on the U.S. cancer research enterprise.

A large majority, 75%, of survey respondents reported that the current federal funding situation is having a direct impact on their ability to conduct cancer research, in many cases triggering "devastating" changes. Delayed clinical trials, the elimination of research staff positions, and the halting or slowing of promising research that could lead to new therapies for cancer were cited as specific results of stagnant funding.

In order to stop these devastating trends and capitalize on forward progress, the NIH and the NCI must have sustained and predictable increases in funding. While private industry is a strong partner in cancer research, they do not conduct the broad scope of clinical research that is important to cancer patients. In contrast, the NCI conducts the high risk, high reward research that leads to practice-changing advancements that industry is often unwilling to undertake – such as pediatric applications, direct comparisons of approved drugs, and providing drugs in combination with or prior to radiation or surgical treatments. Progress in fighting cancer would be faster, more efficient, and more sustainable if funding were steady and sustained.

Our prior investments established the global leadership of American cancer research and care. Without maintenance of those investments, our global leadership and the benefits it offers everyday Americans in both health and economically, are profoundly threatened.

Clinical Trials and Translational Research

NIH-funded translational research and clinical trials have significantly improved the standard of care in many diseases. At the same time, they also have demonstrated more cost-effective treatment options for many common cancers. Unfortunately, these trials are at risk, due to funding concerns that slow the launch and completion of trials. Of great concern is the deterioration of NCI support for federally funded trials that take place in virtually every community in which cancer providers treat patients. On March 1, 2014, the NCI launched the

reorganized National Clinical Trials Network (NCTN). The program currently involves over 3,000 institutions and community-based investigators in the United States and provides approximately 17,000 patients with access to promising new treatments each year, at a $243 million annual cost to taxpayers. Due to funding constraints, the number of patients enrolled in clinical trials has fallen from a peak of almost 30,000 patients in 2009 to a planned enrollment of only 12,000 adults in the current fiscal year and some trials may be forced to close early potentially depriving patients of access to life-prolonging treatments. Please note that without patient accrual to clinical trials, there can be no changes in routine care, practice, and outcomes. This is where science becomes practice changing for patients in America.

We understand that March 1 also marked the end of funding for the NCI Community Clinical Oncology Program (CCOP). NCI is transforming this program into the NCI Community Oncology Research Program (NCORP). NCI is currently reviewing NCORP applications and does not expect to issue notices of award until September 2014. In the meantime, CCOP sites have ongoing ethical obligations to active trial participants to continue clinical trial procedures and required follow-up. At present, community practice sites are expected to do so without any transition in funding. These community sites are crucial to making cutting edge cancer care available to patients in the communities where they live. Without any assurance of sustained funding, some community sites will no longer be able to offer clinical trials to patients.

Clinical trials supported by federal funding have led to important breakthroughs in cancer care that touch every American family and often these are in areas that industry has no incentive to pursue. Typically, the trial concepts are proposed directly by clinician investigators who hypothesize ways to improve treatments for their patients and want to test those hypotheses through rigorously designed prospective clinical trials. Just as the NIH RO1 and R21 grant mechanisms inspire researcher creativity and innovation, the NCTN and NCORP programs are important in fostering research initiatives directly from clinician investigators who see firsthand the importance of answering questions vitalt to their patients. Publicly funded clinical trials involve establishing comparative effectiveness, examining promising regimens, optimizing multimodality treatments, developing therapies for rare cancers, and studying prevention and survivorship strategies. These research goals may run parallel to those of commercial sponsors, but publicly funded trials are designed to benefit patients—not intended to achieve regulatory approval or shareholder interest. Many of these trials are at risk due to funding constraints and the pace of further progress, especially against the most common cancers in America, will slow. For example, at the present time there is no publically funded breast cancer adjuvant treatment trial available in the United States.

ASCO's *Clinical Cancer Advances* report (http://www.cancerprogress.net/clinical-cancer-advances-2013) provides annual recognition of the major advances in patient treatments and care. The 2013 report details 76 research advances, 27 of which received NIH funding, in diseases impacting an estimated 1.6 million patients last year alone. Its top areas of progress include: using genomics to make treatment decisions for individual patients, discovering new cancer subtypes specifically associated with potential new therapies, tackling treatment resistant forms of cancer through precision medicine approaches, enhancing the ability of patients' own immune systems to fight cancer, and implementing new cancer screening paradigms to reduce disparities.

To maintain global American scientific leadership, ASCO urges a substantial increase in funding for the National Clinical Trials Network and NCI Community Oncology Research Program, as well as transition funding for CCOP sites until NCORP launches. ASCO is very concerned that the federal funding situation is causing NCI to propose capping patient participation in clinical trials in order to stretch an ever-shrinking funding pot. NCI acknowledges that current payments are inadequate to cover the costs of conducting trials because they have not increased over nearly a decade. Making the needed increases at the expense of new scientific opportunities, however, is short-sighted and has long-term negative implications. The Institute of Medicine (IOM) recognized this in its 2010 report, *A National Cancer Clinical Trials System for the 21st Century: Reinvigorating the NCI Cooperative Group Program.* The IOM pointed to the notable achievements of Cooperative Group trials that have dramatically improved the outcomes of today's cancer patients and recognized that increases in funding should accompany the changes that the NCI and Cooperative Groups have already implemented to increase the efficiency of their operations and to keep pace with scientific opportunity. An increase in NCI funding would enable the Institute to maintain or increase the number of accruals to trials at the same time as it increases payments to cover the cost of conducting the research.

Threat to America's Global Leadership

While the United States is slowing its investment in medical research, countries around the globe are making significant increases to theirs. Russia is increasing basic research funding by 65%, European investments are increasing by 40% over seven years, South Korea has pledged a 50% increase, and China announced a 26% boost in basic research funding in 2012. These investments result not only in additional research in these countries, but are attracting the best and brightest American-trained scientists to work abroad. The long-term consequences are easy to predict. If scientific progress is achieved elsewhere, Americans will be asked to import new treatments including drugs, intellectual property, and products.

The previously referenced ASCO survey also revealed the disturbing finding that many young investigators are leaving the field altogether due to lack of funding. This too is a predictable effect of funding limits. With more than 35% of survey participants reporting having to lay off skilled staff, many appear to be questioning the viability of a career in research and raising serious concerns about the ultimate impact of budget cuts on patient care and outcomes.

Declining federal funding for clinical trials, coupled with the rising costs of increasingly complex studies, will severely harm the nation's clinical research enterprise by limiting opportunities for innovation and demoralizing young clinical investigators. As opportunities to develop and lead trials diminish and institutional pressures to generate research funding and clinical revenue continue to grow, young investigators may leave the field of research, or choose to pursue research opportunities in other countries. Not only does this threaten our progress against cancer, but it also diminishes the overall scientific workforce in America.

In addition, clinical trials are increasingly being conducted overseas, due to the costs and regulatory complexities of conducting trials in the US. This denies your constituents the opportunity to participate, either as a patient receiving the most promising potential treatment or

as a physician or research nurse conducting the clinical trial. Congress should demonstrate a continued commitment to ensure biomedical research is federally funded.

Because of the incredible scientific opportunities facing us and the current threats to this opportunity, ASCO urges the NIH and NCI to focus more of its resources in the area of clinical trials and translational research.

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ASCO again thanks the Subcommittee for its continued support of cancer patients in the US through funding for the NIH and the NCI. We look forward to working with all members of the subcommittee to advance US cancer research.

Testimony on behalf of the
Population Association of America/Association of Population Centers
Regarding the Fiscal Year 2015 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
By Mary Jo Hoeksema, Director, Government Affairs
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Introduction

Thank you, Mr. Chairman Kingston, Ranking Member DeLauro, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS). These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In FY 2015, we urge the Subcommittee to adopt the following funding recommendations: NIH, $32 billion, consistent with the level recommended by the Ad Hoc Group for Medical Research; NCHS, $182 million, consistent with the Administration's request; and BLS, $610 million, consistent with the Administration's request, at a minimum.

The PAA and APC are two affiliated organizations that together represent almost 4,000 social and behavioral scientists and almost 40 population research centers nationwide that conduct research on the implications of population change. Our members, which include demographers, economists, sociologists, and statisticians, conduct scientific research, analyze changing demographic and socio-economic trends, develop policy recommendations, and train undergraduate and graduate students. Their research expertise covers a wide range of issues,

including adolescent health and development, aging, health disparities, immigration and migration, marriage and divorce, education, social networks, housing, retirement, and labor.

National Institutes of Health

Demography is the study of populations and how or why they change. A key component of the NIH mission is to support biomedical, social, and behavioral 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, 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 U.S. Census Bureau, the number of people age 65 or older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase from about 14 percent of the older population to 21 percent in 2050. To assess the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well-being 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 on the Demography and Economics of Aging, the NIA BSR Division also supports several large surveys that produce accessible data. These surveys include the National Health and Aging Trends Study (NHATS), which has enrolled 8,000 Medicare beneficiaries with the goal of studying late-life disability trends and dynamics. The study also includes a supplement to examine informal caregivers and their impact on the utilization of long-term care by people with

chronic disabilities. Another NIA survey, the Health and Retirement Study (HRS), provides unique information about economic transitions in work, income, and wealth, allowing scientists to study how the domains of family, economic resources, and health interact. The HRS has collected data every two years since 1992, including most recently, biomarkers, from a representative sample of more than 26,000 Americans over the age of 50. These data are accessible to researchers worldwide and have informed numerous scientific findings. For example, in 2013, researchers using the HRS published a study in the *New England Journal of Medicine,* concluding that the cost of providing dementia care is comparable to, if not greater than, those for heath disease and cancer.

<u>*Eunice Kennedy Shriver* National Institute of Child Health and Human Development</u>

Since 1968, NICHD has supported research on population processes and change. This research is housed in the Institute's Population Dynamics Branch, which supports research and training in demography, reproductive health, and population health and funds major national studies that track the health and well-being of children and their families from childhood through adulthood. These studies include Fragile Families and Child Well-Being, the first scientific study to track the health and development of children born to unmarried parents, and the National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health.

One of the most important population research programs that the NICHD supports is the Population Dynamics Centers Research Infrastructure Program. This program promotes innovation, supports interdisciplinary research, translates scientific findings into practice, and develops the next generation of population scientists. In addition, the centers provide incentives to reduce the costs and increase the efficiency of research by streamlining and consolidating

research infrastructure. The population research centers generate and facilitate significant scientific research findings as well. For example, in March 2014, researchers at Johns Hopkins University published findings in *JAMA,* concluding that opening or expanding casinos on California tribal lands not only reduces poverty, but also the obesity rate of children by almost 3 percent.

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 statistical agency that provides data on the health of the U.S. population and supports essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System (NVSS), 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 and influences on health. These surveys include the National Health and Nutrition Examination Survey, National Health Interview Survey (NHIS), and National Survey of Family Growth. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists. The Subcommittee's support of NCHS in recent years has enabled it to make significant progress toward modernizing the NVSS, moving many states from paper-based to electronic filing of birth and death statistics and expediting the release of these data to the user community. Yet, much work is still needed to fully modernize the NVSS and to support necessary expansions to the agency's core surveys so that these data can effectively assess Americans' health.

Bureau of Labor Statistics

The Bureau of Labor Statistics (BLS) produces essential economic information for public and private decision making. Its data are used extensively by population scientists who study and

evaluate labor and related economic policies and programs. The agency also supports the National Longitudinal Studies program and the American Time Use Survey, which are invaluable datasets that the population sciences use to understand how complex factors, such as changes in work status, income, and education, interact to affect health and achievement outcomes in children and adults.

Since FY 2010, the BLS budget has decreased by 10 percent, taking inflation into account. Its bleak fiscal outlook has forced the agency to cut or curtail surveys and put some its programs, such as the export pricing program, in serious jeopardy of complete elimination. Given the importance and unique nature of BLS data, we urge the Subcommittee to support the Administration's request, $610 million, at a minimum, but to consider increasing its funding to $631 million. This additional funding is necessary to restore the agency's purchasing power back to FY 2010 levels and specifically to restore cuts made to the Current Employment Survey and the Quarterly Census of Employment and Wages and to expand the Current Population Survey.

Conclusion

Thank you for considering the importance of these agencies under your jurisdiction that benefit the population sciences. We urge you to give them the highest funding priority as the FY 2015 appropriations process proceeds.

Written Testimony for the Record
to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies
on FY 2015 Appropriations for HIV/AIDS Programs
Submitted by Dr. Carlos del Rio and Dr. Wendy Armstrong of Emory University, and Dr. Melanie Thompson of the AIDS Research Consortium of Atlanta (ARCA)
on behalf of the HIV Medicine Association (HIVMA)
March 28, 2014

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 5,000 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 in the U.S. and globally, lead HIV prevention programs and conduct research that has led to the development of effective HIV prevention and treatment options. We urge you **to invest in the medical research supported by the National Institutes of Health** and sustain and grow funding for **the Ryan White Program at the Health Resources and Services and Administration** and the **Centers for Disease Control and Prevention's (CDC) HIV and STD prevention programs.**

Early access to effective HIV treatment helps patients with HIV live healthy and productive lives and is cost effective.[1] Treatment not only saves the lives of individuals with HIV but has critical benefits to public health in that it reduces risk of transmitting HIV to near zero.[2] However, despite our remarkable progress in HIV prevention, diagnosis and treatment, HIV/AIDS remains a serious epidemic in the United States with a record 1.1 million people living with HIV and an estimated 50,000 new infections occurring annually. In this country, HIV infection disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving health care and treatment. The rate of new HIV infection in African Americans is 8 times that of whites based on population size.[3]

Globally there are more than 35.3 million people living with HIV, the great majority of them in Sub-Saharan Africa but we are also beginning to see improvements in large part due to the U.S. investment in programs like PEPFAR: the HIV prevalence has leveled to about 0.8%, the number of deaths have declined by 30% since 2005 and new infections have declined by 33% since 2001. Still there are 2.3 million new infections each year, more than 6,300 each day.

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 mount an effective response to the domestic HIV epidemic and meet the need in communities across the country.

National Institutes of Health (NIH) – Office of AIDS Research (OAR): HIVMA strongly supports an FY 2015 funding level of at least $32 billion for the NIH, including at least $3.2 billion for the NIH Office of AIDS Research. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of men, women and children in the U.S. and in the developing world. Years of flat funding for biomedical research has eroded our capacity to sustain our nation's historic worldwide leadership in HIV/AIDS research and innovation, and is discouraging cultivation of the next generation of scientists.

Our past investment in comprehensive HIV/AIDS research paid off enormously in dramatic 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. This research also helped reduce the mother to child HIV transmission rate from 25 percent to less than 1 percent in the U.S. and to very low levels in other countries where treatment is available.

Strong, sustained NIH funding is a critical national priority that will foster better health,

economic revitalization and help realize the goals of the National HIV/AIDS Strategy. Sustained increases in funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. Congress should ensure the nation does not delay vital HIV/AIDS research progress.

HIV/AIDS Bureau of the Health Resources and Services Administration: We strongly urge you to increase funding for the Ryan White Program by $123.2 million in fiscal year 2015. For Ryan White Part C programs in FY 15, we urge an allocation of at least $225.1 million, or a $24 million increase over the FY2014 level for Part C. The comprehensive HIV care model or "medical home" that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population. ***The annual health care costs for HIV patients who are not able to achieve viral suppression (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.***[4]

The HIV medical clinics funded through Part C have been struggling to meet the increased demand for patients making an increase in funding critical to prevent additional staffing, laboratory and service cuts. **At a bare minimum, we strongly urge you to support an increase of $24 million over fiscal year 2014 appropriated funding for Ryan White Part C.**

While HIVMA welcomes the $4 million increase for Part C programs proposed in the President's FY 15 budget, we are concerned about the proposal to consolidate Ryan White Part D funding into Part C. Our specific concerns include:

- Part D funding supports effective HIV care and treatment services for vulnerable populations, including women and adolescents. With adolescents accounting for 39% of new HIV infections in the U.S., it is critical to target resources effectively.

- A loss of a Part D program could reduce the community's access to HIV care and treatment as programs are forced to compete or consolidate with Part C clinics.
- Since most Ryan White medical clinics receive funding from multiple parts of the Ryan White Program, reduction of funding to one part can have damaging and unintended consequences to the overall services provided.

While the ACA provides important new health care coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. High cost sharing, benefit gaps and limited state uptake of the Medicaid expansion necessitate a vital and ongoing role for the Ryan White Program.

Center for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP): HIVMA strongly urges total FY2015 funding of **$1.319 billion for the CDC's NCHHSTP**, an increase of $198.2 million over the FY2014 level, **including increases of: $55.1 million for HIV prevention and surveillance, $16.4 million for viral hepatitis** and **$57.4 million for tuberculosis prevention. We also support a funding level of at least $464.3 million for CDC's global health programs, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations. We are especially concerned about flat funding of CDC's global HIV programs, and request an increase of at least $3.3 million to that line item for a total of $132 million.**

The CDC estimates that the 50,000 new HIV infections each year in the U.S generate $56 billion in medical care and lost productivity costs. Support for CDC programs targeting African American and Hispanic/Latino populations is urgently needed as these populations account for more than 60 percent of new HIV cases, particularly affecting the South. A sustained

commitment to HIV prevention funding is critical to enhance HIV/AIDS surveillance and expand HIV testing and linkage to care.

Policy Riders – Remove the Harmful Ban on Federal Funding for Syringe Exchange Programs:

HIVMA strongly urges re-instatement in FY 2015 report language of policy previously enacted into law in FY 2010 and FY 2011 allowing federal funding to be used for syringe exchange programs. Such action will support local control by letting local communities make their own decisions about how best to prevent new HIV and viral hepatitis infections. We cannot afford to dismiss any of the scientifically proven tools in the HIV prevention tool box if we are going to end AIDS in the U.S. and around the globe.

Conclusion: Historically, our nation has made significant strides in responding to the HIV pandemic here at home and around the world, but years of flat funding is now causing us to lose ground, as funding priorities have shifted away from public health and research programs. We must seize the opportunity to limit the toll of this deadly infectious disease on our planet, to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe, and to realize the vision of an AIDS-free generation.

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[1] Kitahata, Gange, Abraham, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. New Engl J Med 2009;360:1815-26.

[2] Cohen, Myron S., et al. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. 2011 New England Journal of Medicine 493-505: V365, no 6, http://www.nejm.org/doi/full/10.1056/NEJMoa11052

[3] CDC Fact Sheet, February, 2014, accessed online at: http://www.cdc.gov/hiv/risk/racialethnic/aa/facts/index.html

[4] Based on data from Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. AIDS Care. 2008:20;1050–6.

House Committee on Appropriations Subcommittee on

Labor, Health and Human Services, Education, and Related Agencies

Public and Outside Witnesses Hearing
March 28, 2014

Testimony for the Record

Submitted by:

The Roundtable on Critical Care Policy

President, Stephanie Silverman

Chairman Kingston, Ranking Member DeLauro and other Members of the Subcommittee, we thank you for holding this important hearing and we appreciate the opportunity to submit testimony for the record. As you work on the Fiscal Year (FY) 2015 appropriations bill, the Roundtable on Critical Care Policy urges the Committee to maintain a strong commitment to funding for the National Institutes of Health (NIH).

The Roundtable strongly believes that if we are to truly improve the health of Americans and reduce the economic burden of disease and illness, it is crucial that continued investments be made in NIH-supported research. The Roundtable urges this Committee to prioritize NIH-sponsored research in the FY2015 appropriations bill.

In addition, the Roundtable believes that one way to foster progress towards advances in treatments, diagnostics and cures is to improve the coordination of research.

Critical care medicine is the care of patients whose illnesses or injuries present a significant danger to life, limb, or organ function and encompasses a wide array of diseases and health issues including respiratory failure, shock, severe infection, traumatic injury, burns, neurological emergencies, and multi-system organ failure. The care provided in the intensive care unit (ICU) is highly specialized and complex due to the extreme severity of illness of its patient population, often involving multiple disease processes in different organ systems at the same time. Each year, five million Americans are admitted into adult medical, surgical, pediatric, or neo-natal ICUs[i]. Providers of critical care require specialized training because the care delivered in the ICU is technology-intensive and the outcomes have life or death consequences. The high resource usage inherent in the ICU often makes care delivery costly, with critical care representing between 17-38% of all hospital costs.

While the critical care community has long been proactive in disseminating new knowledge regarding the pathophysiology and effective treatment of critical illness, we, as a nation, have had disproportionally little focus on critical care research. The U.S. still lags behind other countries in establishing and supporting trial networks for the discovery of new therapies for critically ill patients. Further, a recent study published in the *Journal of Critical Care Medicine* found that despite the fact that cancer care and critical care place similar economic burdens on the U.S., "proportionally 3.1-11.4 times more federal research money was spent on cancer care than on critical care research."[ii]

The unsurprising result is that relatively few breakthroughs have occurred in critical care medicine in decades compared to other areas of medicine. This fact was recently highlighted in an editorial in the New England Journal of Medicine which noted that in 2013 critical care practitioners faced many of the same problems faced by practitioners when the field of critical care was first defined in the 1950s. We can and should do better for patients with critical illnesses.

Clinical advancements that lead to improved outcomes are dependent on a robust research infrastructure that produces new insights and drives innovation. One barrier towards this progress in critical care is likely due to the multidisciplinary nature of the field, resulting in a scattering of critical care related projects throughout the NIH's 27 institutes and across the federal government and very little coordination among the varying entities and researchers.

The Roundtable believes that a Critical Care Coordinating Council within the NIH would help to facilitate information sharing amongst the various Institutes, which would serve to both identify critical care research gaps towards which resources could be more appropriately allocated, as well as identify duplicative projects. Such a Coordinating Council would foster collaboration between the Institutes and strengthen partnerships between the NIH and public and private entities to expand cross-cutting critical care research without costing the Federal government additional money.

There is precedent for this type of entity. The NIH recently acknowledged the efficiencies that can come from increased coordination by establishing an Office of Emergency Care Research, which is intended to serve as hub for basic, clinical and translational emergency care research

and training across NIH. Like emergency medicine, critical care clinicians treat patients across the lifespan who are often facing multiple acute and chronic illnesses and research into this type of medicine does not fit neatly to a specific Institute. Given the impact of critical care medicine on the nation, the Roundtable believes that a Coordinating Council is necessary to ensure our research dollars are utilized most effectively.

With the aging of the baby boomer generation and in the wake of recent health threats, now more than ever it is essential that we advance our scientific research in critical care medicine to ensure that America has a robust critical care infrastructure to appropriately care for seriously ill patients in the future. The Roundtable on Critical Care Policy strongly believes that investments made in medical research—and in particular research aimed at the critically ill and injured—will not only improve health outcomes and maintain U.S. leadership in biomedical research, but will also result in significant overall savings to the health care system. We thank you for your consideration.

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[i] Society of Critical Care Medicine. Critical care statistics in the United States. http://www.sccm.org/AboutSCCM/Public%20Relations/Pages/Statistics.aspx

[ii] Coopersmith CM, Wunsch H, et al. "A comparison of critical care research funding and the financial burden of critical care illness in the United States."*Critical Care Medicine* 40 no.4 (2012)

Testimony for Submission

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To the House Committee on Appropriations
Subcommittee on Labor, HHS, Education and Related Agencies for FY2015

The National Alliance of State & 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 and viral hepatitis programs in the FY2015 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV and viral hepatitis programs in FY2015:

Agency	**Program**	**NASTAD Funding Request**
Health Resources and Services Administration	Ryan White Part B Base	$427.5 million
Health Resources and Services Administration	Ryan White Part B ADAP	$943.3 million
Centers for Disease Control and Prevention	Division of HIV Prevention	$812.7 million
Centers for Disease Control and Prevention	Division of Viral Hepatitis	$47.8 million

The Affordable Care Act (ACA) is radically changing the U.S. health care system. The ACA provides opportunities to increase access for many people living with HIV and/or viral hepatitis to the care and prevention services needed to help end these twin epidemics. However, access to insurance alone does not replace the key role of state public health programs to monitor diseases within their borders. Public health will remain a critical player in meeting the needs of the hardest to reach, most vulnerable populations (e.g., men-who-have-sex-with-men [MSM],

youth, persons who inject drugs) from actively identifying and locating persons at risk, to ensuring linkage to and retention in medical care in a manner that is responsive to the needs of people living with HIV and/or viral hepatitis.

Domestic prevention efforts must match the commitment to the care and treatment of people who are living with HIV. To be successful, we must expand traditional efforts (e.g., outreach and screening for HIV/STDs) and scale-up proven new biomedical prevention modalities such as pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP), while reimaging how the compendium of effective prevention tools can work in tandem to curb incidence in the United States. We must also prioritize funding and efforts to the populations most disproportionately impacted by HIV in the United States – gay men/MSM, especially young gay men/MSM of color. Among the services necessary to improve health outcomes are the needs for linkage to, and retention in care, and access to medications that suppress viral load, reducing HIV transmission, which make HIV more difficult to transmit – ultimately leading to fewer new infections. CDC's prevention programs and the Ryan White Program are crucial to preventing new infections and improving health outcomes.

HIV/AIDS Care and Treatment Programs

The Health Resources and Services Administration (HRSA) administers the $2.3 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV (PLWH). NASTAD requests a minimum increase of **$55.8 million** in FY2015 for state Ryan White Part B grants, including an increase of **$12.8 million** for Part B and **$43 million** for AIDS Drug Assistance Programs (ADAPs). The Ryan White Part B Program funds state health departments to provide care, treatment and support services for low-income uninsured and underinsured individuals living with HIV. With these funds states and territories

provide access to HIV clinicians, life-saving and life-extending therapies, and a full range of vital coverage completion services to ensure adherence to complex treatment regimens. The state ADAPs provide medications to low-income PLWH who have limited or no coverage from private insurance, Medicare and/or Medicaid. In FY2013, over 210,000 clients were enrolled in ADAPs nationwide, an increase of 8% from the previous fiscal year.

Throughout and following the ACA implementation, health departments will require capacity-building support in order to create new infrastructure and leverage existing systems to ensure continuous, high quality care for PLWH. The Ryan White Program will continue to serve PLWH in order to ensure that clients do not experience gaps in coverage or access to treatment.

HIV/AIDS Prevention and Surveillance Programs

NASTAD requests an increase of **$110 million** in FY2015 for CDC's Division of HIV Prevention. The flagship HIV prevention program, HIV Prevention by Health Departments program, funds state and local health departments to provide the foundation for HIV prevention and control nationwide. Health departments are the cornerstone implementers of federal public health policy and are essential to lowering HIV infections. HIV prevention activities and services are targeted to communities where HIV is most heavily concentrated, particularly among racial and ethnic minorities and gay men/MSM of all races and ethnicities.

The number of new HIV infections must decrease to address health threats and improve health outcomes, particularly among disproportionately impacted populations. It is increasingly clear that early detection, linkage to and retention in care, and adherence to treatment will suppress individual and community viral loads and reduce the incidence of HIV. Unfortunately, only a quarter of people living with HIV have an undetectable viral load. Addressing the HIV

care continuum is our newest and most effective tool to get to zero new HIV infections; however, health departments need additional support to successfully implement these strategies.

Robust surveillance systems are essential for high-impact prevention, including using surveillance data for program planning and response, strategically directing resources to populations and geographic areas, and linking and retaining individuals in care. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk and receipt of point of care information, including CD4 and viral load reporting. This will, in turn, contribute to improved testing and linkage to care, retention and re-engagement in care, and reducing risk behaviors.

NASTAD requests that the Committee allow states and localities the discretion to use federal funds to support cost-effective and scientifically proven, syringe services programs (SSPs). Overwhelming scientific evidence has shown SSPs and access to sterile syringes are an evidenced-based and cost-effective means of lowering HIV and viral hepatitis infection rates, reducing use of illegal drugs and helping connect people to HIV and viral hepatitis medical treatment, including substance abuse treatment.

Viral Hepatitis Prevention Programs

NASTAD requests an increase of **$16.3 million** in FY2015 for the CDC's Division of Viral Hepatitis (DVH). This increase will better enable state and local health departments to provide the basic, core public health services to combat viral hepatitis, increase surveillance, testing and education efforts nationwide and effectively implement the recommendations set by the IOM's *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*, the *Action Plan for Viral Hepatitis*, and the CDC testing guidelines for baby boomers. NASTAD requests **$10.4 million** for the viral hepatitis prevention coordinators

(VHPC) program to support and expand programs in all existing jurisdictions. The IOM report and the *Viral Hepatitis Action Plan*, set prevention goals, established program priorities and assigned responsibilities for actions to HHS operating divisions, including CDC. In turn, CDC has provided funds to state and local health departments to coordinate prevention and surveillance efforts via the VHPC. For over a decade, the VHPC program has been and remains the only national program dedicated to the prevention and control of the viral hepatitis epidemics. The CDC estimates that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the United States and as many as 75% are not aware of their infection. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined - a trend that is following the prescription drug overdose epidemic and increasing use of heroin in rural and suburban areas. NASTAD encourages the committee to prioritize disproportionately impacted populations and increase funding for primary prevention efforts.

As you contemplate the FY2015 Labor-Health-Education Appropriations bill, we ask that you consider all of these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV and viral hepatitis 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 epidemics.

Testimony for Submission

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To the House Committee on Appropriations
Subcommittee on Labor, HHS, Education and Related Agencies for FY2015

The ADAP Coalition is a national partnership of HIV local, regional, and national organizations and pharmaceutical companies, who advocate together on behalf of AIDS Drug Assistance Programs (ADAPs). On behalf of The ADAP Coalition, we urge your support for increased funding for ADAPs in the FY2015 Labor-Health-Education Appropriations bill and request a minimum increase of $43 million ($943.3 million total) for ADAPs. We thank you for your consideration of the critical funding needs for ADAPs.

The Health Resources and Services Administration (HRSA) administers the $2.3 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV (PLWH). Ryan White Part B includes ADAPs, which provide medications to low-income individuals with HIV who have limited or no coverage from private insurance, Medicare and/or Medicaid. Some ADAPs also provide insurance continuation and wrap-around services. All states, DC, Puerto Rico, the U.S. Virgin Islands, Guam, American Somoa, the Federated States of Micronesia, the Northern Mariana Islands, Republic of Palau and Republic of the Marshall Islands receive ADAP funding. In FY2013, over 210,000 clients were enrolled in ADAPs nationwide, an increase of 8% from the previous fiscal year.

ADAPs are funded through a three-pronged approach, federal funding, state funding and savings from pharmaceutical manufacturers. Federal investment in ADAPs has fallen from 68%

of the total ADAP budget in FY2000 to 39% of the total ADAP budget in FY2013, despite increases in client enrollment and utilization.

In 2008, ADAPs began a period of crisis that led to the institution of cost containment measures including waitlists. These waitlists peaked at 9,298 in September 2011. In FY2013, ADAPs received $886 million in federal funding, a decrease of $47 million from FY2012. The Obama Administration authorized a transfer of $35 million in Emergency Relief Funding (ERF) for ADAPs. This was in addition to $40 million in ERF from previous fiscal years. ADAP was funded at $900.3 million in FY2014. On November 21, 2013, South Dakota transitioned its 11 remaining eligible clients into their ADAP, marking the first time since January 2008 that there were no individuals on ADAP waiting lists in the United States. States were able to clear waiting lists with influx of ERF from the federal government and the continued pricing stability from ADAP partnerships with manufacturers.

The HIV Care Continuum begins with diagnosing HIV infections, ensuring they are diagnosed early and linked to high quality care to achieve maximum health outcomes, which includes an undetectable viral load. HIV treatment is a crucial aspect of prevention, as research indicates that people who are on antiretroviral therapy can reduce their risk of transmission to others by 96%. Among the services necessary to improve health outcomes are the needs for linkage to, and retention in care, and access to medications that suppress viral load, reducing HIV transmission, which leads to fewer new HIV infections. Access to medication through ADAP is crucial to preventing new infections and improving health outcomes.

The Affordable Care Act (ACA) is dramatically changing the U.S. health care system. The ACA provides opportunities to increase access for many people living with HIV to the care and prevention services needed to help end the epidemic. ADAPs will continue to provide

medications directly and access to insurance through premium and co-pay assistance throughout and after the ACA is implemented. However, access to insurance alone does not replace public health programs that actively identify and locate persons at risk, nor does access to insurance ensure linkage to and retention in medical care in a manner that is responsive to the needs of persons living with HIV. Health departments will require capacity-building support in order to create new infrastructure and leverage existing systems to ensure continuous, high quality care for people living with HIV. The Ryan White Program will continue to serve PLWH in order to ensure that clients do not experience gaps in coverage or access to treatment.

Increasing funding to ADAPs is critical to ending the HIV epidemic so that ADAPs can continue to provide a full range of services for people living with HIV. As you contemplate the FY2015 Labor, HHS and Education Appropriations bill, we ask that you consider all of this critical funding need. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations.

Centers for Disease Control and Prevention (CDC) Coalition

C/o American Public Health Association 800 I Street NW Washington, DC, 20001 202-777-2514

Donald Hoppert, Director, Government Relations, American Public Health Association

Testimony submitted for the record on March 28, 2014
House Appropriations Subcommittee on Labor,
Health and Human Services, Education and Related Agencies

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our nation's prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs.

We believe Congress should support CDC as an agency, not just the individual programs that it funds. Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, we urge a funding level of $7.8 billion for CDC's programs in FY 2015. We appreciate some of the important new investments in President Obama's FY 2015 budget proposal including those for prescription drug overdose prevention, antimicrobial resistance and global health security; however, under the president's proposal, CDC's budget would be cut by nearly $243 million compared to FY 2014. CDC's budget authority under the president's budget is lower than FY 2003 levels. State and local health departments continue to operate on tight budgets and with a smaller workforce, losing more than 50,000 public health jobs since 2008. These cuts will reduce the ability of CDC and its state and local grantees to investigate and respond to public health emergencies, ensure adequate immunization rates and track environmental hazards.

CDC is a key source of funding and technical assistance for state and local programs that aim to improve the health of communities. CDC funding provides the foundation for state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. CDC serves as the command center for our nation's public health defense system, conducting surveillance and detection of 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, CDC is the nation's expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC serves as the lead agency for bioterrorism and public health emergency preparedness and must receive sustained support for its preparedness programs to meet future challenges. We urge you to provide adequate funding for CDC's emergency preparedness and response activities.

Heart disease is the nation's No. 1 killer. In 2010, over 597,000 people in the U.S. died from heart disease, accounting for nearly 25 percent of all U.S. deaths. More males than females died of heart disease in 2010, while more females than males died of stroke that year. Stroke is the fourth leading cause of death and is a leading cause of disability. In 2010, more than 129,000 people died of stroke, accounting for about one of every 19 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and the Million Hearts program work to improve cardiovascular health.

Cancer is the second most common cause of death in the U.S. More than1.6 million new cancer cases and 585,720 deaths from cancer are expected in 2014. In 2009 the overall cost for cancer in the U.S. was more than $216.6 billion: $86.6 billion for direct medical costs, $130 billion for indirect mortality costs. CDC's National Breast and Cervical Cancer Early Detection Program helps millions of 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 all 50 states to develop comprehensive cancer control 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.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's Office of Smoking and Health funds important programs and campaigns to prevent tobacco addiction and to help those who want to quit. We must continue to support these vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the 25.8 million Americans who have diabetes, nearly 7 million cases are undiagnosed. In 2010, about 1.9 million people aged 20 years or older were newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were $245 billion in 2012. The Division of Diabetes Translation funds critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. While the obesity rates among children between the ages of 2-5 have significantly decreased over the past decade, more than one-third of adults are obese and 17 percent of children are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. CDC funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity.

Arthritis is the most common cause of disability in the U.S., striking more than 52 million Americans of all ages, races and ethnicities. CDC's Arthritis Program plays a critical role in addressing this growing public health crisis and working to improve the quality of life for individuals affected by arthritis.

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, 16 percent of who are undiagnosed. 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 more than 636,000 in the U.S. and is devastating populations around the globe.

The U.S. has the highest rates of sexually transmitted diseases in the industrialized world. Nearly 20 million new infections occur each year. CDC estimates that STDs, including HIV, cost the U.S. healthcare system almost $16 billion annually. An adequate investment in CDC's STD prevention programs could save millions in annual health care costs in the future.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. 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 are an essential part of the nation's statistical and public health infrastructure and must be adequately funded.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination among adults as well, with significant racial and ethnic disparities in vaccination levels persisting among the elderly. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, $10.20

is saved in direct and indirect costs. An estimated 20 million cases of disease and 42,000 deaths are prevented each year through timely immunization.

Injuries are the leading causes of death for people ages 1-44. Unintentional injuries and violence, such as older adult falls, prescription drug overdose, child maltreatment and sexual violence, account for approximately 29 percent of emergency department visits each year. Annually, injury and violence cost the U.S. approximately $406 billion in direct and indirect medical costs. The National Center for Injury Prevention and Control works to prevent injuries and minimize their consequences by researching the problem, identifying the risk and protective factors, developing and testing interventions and ensuring widespread adoption of proven prevention strategies.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects who survive often experience lifelong physical and mental disabilities. Over 500,000 children are diagnosed with a developmental disability and more than 50 million people in the U.S currently live with a disability. The National Center on Birth Defects and Developmental Disabilities conducts important programs to prevent birth defects and developmental disabilities and promote the health of people living with disabilities and blood disorders.

The National Center for Environmental Health works to protect public health by helping to control asthma, protecting from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. To ensure it can carry out these vital programs, we ask you to support and restore adequate funding for NCEH.

In order to meet the many ongoing public health challenges outlined above, we urge you to support our **FY 2015 request of $7.8 billion for CDC's programs.**

Written Testimony

FY15 Funding: Bureau of Health Professions at the Health Resources and Services Administration

Prepared for presentation to the U.S. House of Representatives
Appropriations Subcommittee on
Labor, Health & Human Services, Education, and Related Agencies

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March 28, 2014

Mr. Chairman, Ranking Member, and distinguished Members of the Subcommittee, the members of the **Hispanic Dental Association (HDA),** the leading voice for Hispanic oral heath working for the elimination of oral health disparities, are requesting that Title VII and VIII FY2015 funding for the **Bureau of Health Professions** and **Nurses Programs** at the **Health Resources and Services Administration (HRSA)** be appropriated at a recommended level of $520 million. Furthermore, we recommend maximized funding of the **Health Professions Training for Diversity** and the **Oral Health Training Programs** at HRSA's Bureau of Health Professions, which are of particular interest to HDA members.

The State of Hispanic Oral Health

Hispanic families and their children disproportionately suffer the effects of poor oral health and the U.S. Hispanic population lags behind the general population when it comes to their knowledge of basic oral health. A recent HDA-led survey "Hispanics Open Up About Oral Health" found misperceptions and knowledge gaps among the Hispanic community. For example, almost one-third of Hispanics (30%) believe that cavities will go away on their own if

you brush regularly, which is false. To echo this finding, a *CDC NCHS Data Brief (No. 104, Aug. 2012)* reports Hispanic children and adolescents continue have the highest levels of untreated dental decay in the United States. Further examples include:

- 46% of Hispanics do not know, or incorrectly believe to be false that poor oral health may be linked to other health complications, including stroke, heart disease and diabetes.
- Hispanics rely equally on their parents, 61%, and their dentist/hygienist, 60%, as sources for oral care information.
- 82% of Hispanic parents consider themselves excellent or good sources for teaching their children about good oral health habits.
- 59% of Hispanics feel that more Hispanic dentists/hygienists in their community would be similarly helpful.

In 2009, when the Heath Resources and Services Administration (HRSA) and the California HealthCare Foundation asked the Institute of Medicine (IOM) and the National Research Council (NRC) to organize a committee to address access for oral health care for vulnerable and underserved populations in America, one of the two principles the committee established to guide its deliberations was, "Oral health promotion and disease prevention are essential to any strategies aimed at improving access to care." The statistics cited above underscore a true need for oral health education, prevention and treatment among the Hispanic population. After all, better oral health education for Hispanics encourages preventive services that are always more cost effective. People understand that they should to go to the dentist, but don't know why and how it impacts their overall health, quality of life, and bank account. Through these measures, the misperceptions Hispanics have about oral health can be addressed.

In addition, we must work to address dental workforce shortfalls to increase the number of underrepresented minorities in health professions schools as well as promote cultural and linguistic competence in the health professions. In fact, the *Council on Graduate Medical Education (COGME)*, a committee authorized by Congress in 1986, has issued reports calling

for the need to increase underrepresented minorities (URMs) in health professions. Underrepresented minorities comprise more than 25% of the U.S. population and are projected by the Census Bureau to increase to 39% by 2050. However, URMs account for only approximately 7% of dentistry. Moreover, oral health literacy (knowledge gaps) and cultural and linguistic competencies profoundly influence how health professionals deliver quality health care and present significant barriers to many Hispanics.

Preserve & Strengthen Oral Health Prevention, Promotion & Infrastructure Programs

The Bureau of Health Professions works to support the training and development of health professionals to improve the healthcare of our society, including vulnerable populations. The bureau has made as one of its five priorities to "Reduce health disparities by increasing health care workforce diversity." HRSA understands that one key to reducing health disparities due to factors such as socioeconomics, race, or ethnicity, among others, is by increasing the diversity of the health professions workforce. According to HRSA, research indicates that health professionals who identify as underrepresented minorities are more likely to serve in those areas of need. Moreover, HRSA also understands that increasing cultural competency training for all health professionals is critical to addressing health care disparities.

- During Academic Year 2012-13, 45% of graduates and program completers participating in the bureau-supported health professions training and loan programs were underrepresented minorities and/or from disadvantaged backgrounds.
- The rate for oral health programs was 42%.
- 60% of oral health training programs took place in a medically underserved community.

Health Professions Training for Diversity

The Centers of Excellence (COE) Program, which has a goal to recruit, train, and retain URM students and faculty to increase the supply and quality of URMs in the health professions workforce, and the Scholarships for Disadvantaged Students (SDS) Program, which awards scholarships to students from disadvantaged backgrounds with financial need, many of whom

are URMs, are two programs from which dentistry, among many health professions, benefits. In academic year 2012-2013, 43% of trainees reached through COE were Hispanic. Overall, there were 7,600 trainees across the country. The SDS Program was just as effective. In Academic Year 2012-13, scholarships were provided to 4,889 students from disadvantaged backgrounds. Approximately 3 out of every 5 students who received an SDS-funded scholarship are considered underrepresented minorities in their respective professions. Moreover, 80% of graduates indicated an intention to work or pursue training in medically underserved communities.

Oral Health Training Program

The Oral Health Training Program offers programs that work to increase access to culturally competent oral health and dental professionals that provide oral health services to underserved communities. Under this program, training exists for General Pediatric, Public Health Dentistry and Dental Hygiene, and State Oral Health Workforce Improvement. In Academic year 2012-13, Oral Health Training Programs trained more than 2,600 oral health students, exceeding the performance goal of 1,800 by 48%. Also, grantees of the Oral Health Training Programs were able to train 517 primary care dental residents and 60% received clinical training in a medically underserved community. Additional data of note:

- 1 out of every 8 students, residents, and fellows who received a financial award reported coming from a disadvantaged background, and

While these figures are encouraging, HDA contends more can be done by the federal government to support these worthy programs.

HDA believes that improving the existing oral health team with expanded function dental assistants and dental hygienists helps to more efficiently deliver care and oral health education. Presently, many states have limited functions placed on these vital oral health

auxiliaries and this practice must end for the benefit of the public. Again, HDA views these programs as being crucial components to efforts to eliminate health disparities because they help to remove the many barriers to care, which include social, economic, and cultural, among other. However, HDA does not support funding for the Alternative Dental Health Care Provider Demonstration Project under this program.

RECOMMENDATION

The nation's 53 million Hispanics comprise 17% of the total U.S. population, according to the Pew Hispanic Center. Therefore Hispanics, the fastest growing segment of the U.S. population, according to the U.S. Census Bureau, has significant barriers to overcome to achieve better oral health. As the Institute of Medicine's July 2011 report brief states, "Oral health is an integral part of overall health, and therefore, oral health care is an essential component of comprehensive health care." Proper funding of the Bureau of Health Professions at HRSA is essential to the overall health and well-being of our fellow Americans. We contend HRSA programs help to address the need for diversity in health care professions.

Therefore, based upon the merits of the programs, and the integral part they play to address health care disparities, we respectfully request the Subcommittee fund the Bureau of Health Professions and Nursing Program at the Health Resources Services Administration (HRSA) at a recommended level of $520 million and maximize funding for the Health Professions Training for Diversity and the Oral Health Training Programs at HRSA's Bureau of Health Professions so that they can continue to meet the needs of reducing health disparities and addressing cultural competency by increasing health care workforce diversity in our society. Thank you for the opportunity to present our written testimony before the Subcommittee.

Eldercare Workforce Alliance
Outside Witness Testimony - Fiscal Year 2015 Appropriations
Subcommittee Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
March 28, 2014

Written Testimony** Regarding Funding Requests for Eldercare Workforce Programs
of the Department of Health and Human Services

Submitted on behalf of the Eldercare Workforce Alliance
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By

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Mr. Chairman, Ranking Member DeLauro, and Members of the Subcommittee:

We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 30 national organizations united to address the immediate and future workforce crisis in caring for an aging America. As the Subcommittee begins consideration of funding for programs in FY 2015, the Alliance** urges you to provide adequate funding for programs designed to increase the number of health care professionals prepared to care for America's growing senior population and to support family caregivers in the essential role they play in this regard.

Today's health care workforce is inadequate to meet the special needs of older Americans, many of whom have multiple chronic physical and mental health conditions and cognitive impairments. Without a national commitment to expand training and educational opportunities, the workforce will be even more constrained in its ability to care for the growth in the elderly population as the baby boom generation ages. Reflecting this urgency, the Health Resources and Services Administration (HRSA) has identified "enhancing geriatric/elder care training and expertise" as one of its top five priorities. Of equal

*** The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. This testimony reflects the consensus of the Alliance and does not necessarily represent the position of individual Alliance member organizations.*

importance is supporting the legions of family caregivers who annually provide billions of hours of uncompensated care that allows older adults to remain in their homes and communities. The estimated economic value of family caregivers' unpaid care was approximately $450 billion in 2009.

The number of Americans over age 65 is expected to reach 70 million by 2030, representing a 71% increase from today's 41 million older adults. That is why Title VII and Title VIII geriatrics programs and Administration on Aging programs that support family caregivers are so critical to ensuring there are skilled eldercare workers and well-supported family caregivers available to meet the complex and unique needs of older adults.

We hope you will support a total of $44.7 million in funding for geriatrics programs in Title VII and Title VIII of the Public Health Service Act and $173.9 million in funding for programs administered by the Administration for Community Living. Specifically, we recommend the following levels:

- **$39.7 million for Title VII Geriatrics Health Professions Programs;**
- **$5 million for Title VIII Comprehensive Geriatric Education Programs;**
- **$172.9 million for Family Caregiver Support Programs; and**
- **$3 million for a White House Conference on Aging.**

EWA specifically requests the following levels of funding:

Title VII Geriatrics Health Professions Programs: Appropriations Request: $39.7 Million

Title VII Geriatrics Health Professions programs **are the only** federal programs that seek to increase the number of faculty with geriatrics expertise in a variety of disciplines. These programs offer critically important training for the healthcare workforce overall to improve the quality of care for America's elders.

- Geriatric Academic Career Awards (GACA): **EWA requests $5.5 million.** The goal of this program is to promote the development of academic clinician educators in geriatrics. *Program Accomplishments*: In the In the Academic Year 2012-2013, the GACA program funded 62 full-time junior faculty. These

awardees delivered over 1,100 interprofessional continuing education courses specific to geriatric-related topics to over 53,000 students and providers. Additionally, they presented research at 215 local, state and national conference and published 108 peer-reviewed publications. HRSA, through the Affordable Care Act (ACA), expanded the awards to be available to more disciplines. EWA strongly supports this expansion and requests adequate funding to reflect this change. Currently, new awardees are selected only every five years. To meet the need for clinician educators in all disciplines, EWA believes that awards should be made available to clinical educators annually in order to develop an adequate number of faculty that can provide geriatric instruction and training.

- Geriatric Education Centers (GEC): **EWA requests $20 million.** The goal of Geriatric Education Centers is to provide high quality interprofessional geriatric education and training to current members of the health professions workforce, including geriatrics specialists and non-specialists. *Program Accomplishments*: In Academic Year 2012-2013, the 45 GEC grantees developed and provided over 1,650 different continuing education and clinical training offerings to more than 135,000 health professionals, students, faculty, and practitioners, significantly exceeding the program's performance target. Three quarters of the continuing education offerings were interprofessional in focus. Of the sites that offered clinical training sessions, 2 out of every 5 of these sites were in a medically underserved community and/or Health Professional Shortage Area.
- Alzheimer's Disease Prevention, Education, and Outreach Program (GECs): **EWA requests $5.3 million.** These funds allow HRSA to expand efforts to provide interprofessional continuing education to health care practitioners on Alzheimer's disease and related dementias, utilizing the already existing Geriatric Education Centers (GECs).

- Geriatric Training Program for Physicians, Dentists, (GTPD) and Behavioral and Mental Health Professions: **EWA requests $8.9 million**. The goal of the GTPD program is to increase the number and quality of clinical faculty with geriatrics competence, including retraining mid-career faculty in geriatrics. *Program Accomplishments:* In Academic Year 2012-2013, a total of 64 physicians- including psychiatrists-, dentists, and psychologists, were supported through this fellowship program. Fellows delivered over 275 courses to 5,600 trainees. This program supports training additional faculty in medicine, dentistry, and behavioral and mental health so that they have the expertise, skills, and knowledge to teach geriatrics and gerontology to the next generation of health professionals.

Title VIII Geriatrics Nursing Workforce Development Programs: Appropriations Request: $5 million

This program supports additional training for nurses who care for the elderly; development and dissemination of curricula relating to geriatric care; training of faculty in geriatrics; and continuing education for nurses practicing in geriatrics.

- Comprehensive Geriatric Education Program: The goal of this program is to provide quality geriatric education and training to individuals caring for the elderly. *Program Accomplishments*: In Academic Year 2012-2013, a total of 18 Comprehensive Geriatric Education Program (CGEP) grantees provided a variety of services, including over 150 different continuing education courses to over 11,600 trainees.
- Traineeships for Advanced Practice Nurses: The Comprehensive Geriatric Education Program was expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing, or other nursing areas that specialize in care of older adults. In Academic Year 2012-2013, a total of 74 grantees were awarded traineeships.

Administration for Community Living Family Caregiver Support and White House Conference on Aging: Appropriations Request: $175.9 million

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

- Family Caregiver Support Services: **EWA requests $154.5 million.** This program provides a range of support services to approximately 700,000 family and informal caregivers annually in States, including counseling, respite care, training, and assistance with locating services that assist family and informal caregivers in caring for their loved ones.
- Native American Caregiver Support: **EWA requests $6.4 million.** This program provides a range of services to Native American caregivers, including information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services.
- Alzheimer's Disease Support Services: **EWA requests $9.5 million.** One critical focus of this program is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. It funds evidence-based interventions and expands the dementia-capable home and community-based services.
- Lifespan Respite Care: **EWA requests $2.5 million.** This program funds grants to improve access to respite care for family caregivers of children or adults with special needs.
- White House Conference on Aging: **EWA requests $3 million.** Recommended by the Commission on Long-Term Care, the President's FY2015 budget request includes funding for a decennial White House Conference on Aging bringing together stakeholders and consumers to discuss aging issues.

On behalf of the members of the Eldercare Workforce Alliance, thank you for your past support for geriatric workforce programs. We ask that you join us in supporting the geriatrics workforce at this critical time – for all older Americans deserve quality care, now and in the future.

Testimony in Support of the State Paid Leave Fund

Submitted to the U.S. House of Representatives Committee on Appropriations

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

Ellen Bravo, Executive Director, Family Values @ Work

March 28, 2014

Nearly two decades ago, I was appointed by Congress to a bipartisan Commission on Leave to study the impact of the FMLA on employers and employees. Our report, "A Workable Balance," included a unanimous recommendation that states experiment with forms of wage replacement funds for those on FMLA leave. The Stare Paid Leave Fund in the President's budget is an excellent tool to make that happen.

As the Executive Director of Family Values @ Work, I respectfully urge the Committee on Appropriations to include the State Paid Leave Fund, administered through the Department of Labor, in the Fiscal Year 2015 Labor, Health and Human Services and Education bill. The bill should include the $105 million funding proposed in the President's budget. The State Paid Leave Fund would create a competitive federal grant fund designed to spur innovation among states interested in creating family and medical leave insurance (FMLI) programs, as well as those with established FMLI programs, and has the potential to help millions of American families.

Family Values @ Work is a multi-state consortium of 21 state coalitions working for paid sick days, family leave insurance and other policies that value families at work. Our network includes California, New Jersey and Rhode Island, each of which have successfully launched family and medical leave insurance funds, as well as states like Colorado, Connecticut, New York, Vermont, and Washington, among others, who are actively working to establish laws to create these insurance programs.

At some point in their working lives, almost all Americans will need to take time off to care for a new baby or adopted child, an ailing child or parent, or their own health. The Family and Medical Leave Act – the only federal law designed to help working people meet the dual demands of job and family – leaves out 40 percent of the workforce and guarantees only unpaid leave, which millions cannot afford to take. And only 12 percent of the U.S. workers currently have access to paid family leave through their employers. That means millions of workers who develop serious health conditions, have seriously ill family members or become parents are forced to choose between what is best for them and their families and income they need to cover basic expenses.

Family and medical leave insurance programs at the state level allow workers to pay a small portion of their wages each week for the guarantee that when they need it, they can receive a percentage of their wages while they have to take extended family or medical leave from work. These programs help working families stay afloat when they need time off to care for an ill family member, a new baby or their own health.

Research on programs in California, and New Jersey has shown that paid leave contributes to increased family financial stability and improved child well-being, better workforce outcomes for new parents, reductions in government public assistance expenditures, and cost-savings for businesses.

That's why there is broad support among the business community for paid family and medical leave programs. Businesses understand it's good for their bottom line. California employers report that the program has had a neutral or positive effect on employee productivity, profitability, and turnover, and most employers coordinate their own benefits with the state's PFL program. A 2011 study of California's FMLI program estimated that it would save employers $89 million a year. A recent Rutgers study shows that New Jersey's FMLI program has saved businesses money by improving employee retention, decreasing turnover costs, and improving productivity.

A federal grant program would help states with one-time start-up costs to develop and implement successful family and medical leave insurance programs that are so needed across the country. Once these insurance programs are up and running they become self-sustaining. Without this federal support, the initial capital needed to design and launch these programs would continue to act as a roadblock, despite broad public support.

This fund would directly benefit states in our network – both states considering a family leave and medical insurance program and states with an existing FMLI program. States with established FMLI programs, like California, New Jersey and Rhode Island, could

apply for grants to increase awareness about and utilization of the program by conducting outreach to ensure eligible workers who have been paying into the program are accessing it when they need it. For the many states considering programs, access to competitive federal grants that help defray the one-time costs of designing and launching these insurance programs would provide a compelling incentive to states to innovate. In the case of the SPLF, a modest investment at the federal level would translate to significant and immediate impact for millions of families' economic security.

In sum, there is tremendous support across the country for creating a new State Paid Leave Fund. I urge you to pass a budget bill with $105 million allocated for the State Paid Leave Fund to help states like those in Family Values @ Work's network with programs that benefit working families, businesses, and the local economy.

US House of Representatives
Committee on Appropriations
Subcommittee on Labor, Health and Human Services,
Education, and Related Agencies

Hearing

Tuesday, March 25, 2014 10:00 AM

Written Testimony Submitted by the
National Adult Protective Services Association (NAPSA)
Kathleen M. Quinn, Executive Director

1,000 Thousand Victims A Day

The $25 million Elder Justice Act Funding Request for the HHS Administration on Community Living/Administration on Aging is urgently needed to adequately respond to victims as described below:

A state Adult Protective Services (APS) worker responded to a call about an 83-year-old woman living in her home under deplorable conditions, bedridden and suffering from dementia. Her 52-year-old son lived with her as her caregiver.

The woman appeared to have been neglected for an extended period of time and was confined to her bed, living in her own filth and infested with maggots. Her unemployed son had taken over $50,000 from his mother's bank accounts to buy a car and to gamble at casinos.

Also living in the home was a 48-year-old severely developmentally disabled daughter, also found living in filth and without adequate nutrition, as well as numerous malnourished dogs.

The APS worker took emergency measures to get medical evaluations and treatment for the mother and daughter, found an alternative living situation for the mother, worked with a local disabilities advocacy organization to place and assist the daughter, contacted animal control to take the dogs, had the house cleaned up. APS also referred the case to law enforcement, resulting in the son being arrested and charged with felony counts of criminal neglect and theft.[1]

The above is a description of an actual (and not atypical) elder and vulnerable abuse case that was handled by APS. Without APS, this older woman and her developmentally disabled adult daughter would have continued to suffer in the terrible conditions in which they were held captive, and their abuser son and brother would have never been held accountable for his cruelty and greed.

Research tells us that there are more elder abuse victims than victims of other types of abuse such as child abuse and domestic violence.[2] Research also estimates that ten percent of persons 60 and older are abused every year. This means that of the 10,000

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[1]Quinn, K. & Benson. W. (2012). The States' Elder Abuse Services: A System Still in Search of Support. Generations. 36-3, 68.
[2] Sedlak, A.J., Mettenburg, J., Basena, M., Petta, I., McPherson, K., Greene, A., and Li, S. (2010). Fourth National Incidence Study of Child Abuse and Neglect (NIS–4): Report to Congress. Washington, DC: U.S. Department of Health and Human Services, Administration for Children and Families. http://www.acf.hhs.gov/programs/opre/abuse_neglect/natl_incid/index.html .
ONE DEPARTMENT: OVERVIEW of ACTIVITIES ON VIOLENCE AGAINST WOMEN 2008-2009. DHHS Office of Women's Health http://www.womenshealth.gov/owh/pub/violence-against-women.cfm.

people a day who are turning 65, 1,000 of them are, have been or will likely be victims of elder abuse.[3]

Yet, older victims and adult victims with disabilities are the only victims of crime and abuse who receive no designated federal support for services. This is true even though federal support and attention to other types of abuse have been successful, resulting in, for example, reduced incidences of both child abuse and domestic violence homicides.[4]

Similar success can eventually be achieved if the Elder Justice Act is funded, starting with the FY 2015 modest request of $25 million to begin the development of a national infrastructure for Adult Protective Services.

Elder abuse causes great physical and emotional suffering, and results in greatly increased rates of hospitalization and premature death. *It is also extremely expensive, to the victims and their families, to financial institutions, and to taxpayers.* There are many older persons, for example, who must rely on Medicaid to pay for their long-term care after all their funds have been stolen from them.

APS Programs comprise the only victim services system in place in every community to go into the homes of these vulnerable adults to protect them from further abuse. Without federal support and leadership, APS Programs have evolved independently in every state,

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[3]Acierno, R., Hernandez, M. A., Amstadter, A. B., Resnick, H. S., Steve, K., Muzzy, W., & Kilpatrick, D. G. (2010). Prevalence and correlates of emotional, physical, sexual, neglectful, and financial abuse in the Congressional Record Feb. 10, 2003. http://thomas.loc.gov/cgi-bin/query/R?r108:FLD001:S02121United States: The National Elder Mistreatment Study. American Journal of Public Health, 100, 292-297.

[4] Dugan, L, Nagin, D & Rosenfeld, R. (2003) Do Domestic Violence Services Save Lives? NIJ Journal. 250 NIJ Journal 250 (November 2003): 20–25, NCJ 196548.

meaning that the training, standards, eligibility thresholds and resources available can differ dramatically from state to state and even from county to county. There are no national definitions, standards of practice, training and educational requirements, supervisor protocols, caseload standards, data systems or other basic prerequisites of well-developed social services programs.

It must be noted that APS in thirty-four states do receive funding through the federal Social Services Block Grant (SSBG) wherein each state decides how to allocate the federal block grant among its varied social services programs. In a recent NAPSA poll, 71% of the respondents in states which rely on SSBG funding for APS stated that loss of the funding would be either a very significant blow to, or would completely eliminate, their APS programs. Although it is sometimes stated that SSBG funds duplicate other federal funding, that is clearly not the case with APS, which receives no other federal monies. Social Services Block Grant funds are essential to maintaining APS services for vulnerable adult victims in every state, and the additional, APS-specific funding through the Elder Justice Act is critically needed to bring all APS programs up to minimum standards nationwide.

After over three decades of hearings and reports on the issue of elder abuse, we respectfully request that this Committee and this Congress heed the cries of these hidden victims of abuse, neglect and exploitation by supporting both Elder Justice Act and SSBG funding to insure that an adequate protective services system is available to victims in every community.

Thank you.

Lindsey Copeland
Director of Policy and Legislative Affairs
National Association of States United for Aging and Disabilities (NASUAD)

Written Testimony for the Record

Thank you to the Members of the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the opportunity to submit this written testimony. As you work to develop Fiscal Year (FY) 2015 funding priorities, the National Association of States United for Aging and Disabilities (NASUAD) urges you to consider the Administration for Community Living's (ACL) FY15 request for $25 million to address the all-too prevalent problem of elder abuse. This investment would support initial implementation of the Elder Justice Act's (EJA) Adult Protective Services (APS), research, and evaluation activities.

NASUAD represents the 56 officially designated state and territorial agencies on aging and disabilities. Each of our members oversees the implementation of the Older Americans Act (OAA), and many also serve as the operating agency in their state for Medicaid waivers that serve older adults and individuals with disabilities. Together with our members, we work to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability, and their caregivers.

According to ACL, an estimated 2.1 million older Americans are victims of elder abuse, neglect, or exploitation each year. As the nation's older population increases, so too does the incidence of elder abuse. While there is no single set of national elder abuse prevalence data, the number of reported cases is on the rise. A 2004 national survey of state APS programs showed a 16 percent increase in the

number of elder abuse cases from an identical study conducted in 2000. Additionally, an overwhelming number of cases of abuse, neglect, and exploitation go undetected and untreated each year. Experts estimate that for every case of elder abuse or neglect reported, as many as five cases go unreported.

Despite the clear and growing need, there is no dedicated federal funding for, or corresponding federal oversight of, elder abuse prevention services. Absent a national framework, states have been left to address this issue independently from one another, and must rely on multiple funding streams to support their work, ultimately resulting in a fragmented system. Though each state has developed an APS program that responds to reports of elder abuse, neglect, and exploitation, these programs vary greatly from state to state - from the populations they serve, to the reporting mechanisms they use, and the budget structures under which they operate. These discrepancies, which continue to be exacerbated by the lack of federal APS funding, necessarily impede efforts to compare, evaluate, and improve state approaches to reducing and preventing elder abuse.

To address the systemic inadequacies in our nation's approach to eradicating elder abuse, neglect, and exploitation, we urge you to support ACL's request of $25 million in discretionary funding to implement the EJA in FY15. As an integral part of ACL's Elder Justice Initiative, this funding would be used to develop much-needed program standards and data collection efforts, as well as to support the implementation of a nationwide APS data system; these dollars would also fund research activities, including efforts to translate promising interventions from other violence prevention areas to elder abuse, and evaluations of the effectiveness of these interventions

NASUAD believes that efforts to improve the response to, awareness of, and intervention in elder abuse, neglect, and exploitation could be more effectively coordinated through the establishment of a national APS program. Accordingly, we urge you to fully fund ACL's FY15 Elder Justice Initiative.

Thank you for the opportunity to provide input on this critical issue, and for your leadership. NASUAD looks forward to working with all of you to preserve the dignity, independence, and health of older adults, and to protect those who may no longer be able to protect themselves.

House Committee on Appropriations Subcommittee on

Labor, Health and Human Services, Education and Related Agencies

Public Witness Hearing, March 25, 2014

Statement submitted by:

M. Cindy Hounsell, President, Women's Institute for a Secure Retirement

The Women's Institute for a Secure Retirement (WISER) is pleased to submit this written statement in support of elder justice funding and the Elder Justice Act. WISER is a non-profit organization whose mission is to improve the long-term financial security of all women (and families) through education and advocacy. 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 research, training workshops, education materials and outreach. WISER operates the National Education and Resource Center on Women and Retirement Planning under a cooperative agreement with the U.S. Administration on Aging. The Center focuses on the economic challenges women face and aims to help women develop strategies for addressing them, including protecting themselves from elder financial fraud and abuse.

Elder financial abuse became a "growth industry" in the beginning of the 21st century, and these crimes affect hundreds of thousands of elderly persons each year. As the holders of the largest percentage of wealth, and with access to vast equity reserves in family homes, the elderly are prime targets of a growing number of unethical professionals using fear tactics to sell products that are often inappropriate. Women are especially vulnerable. Even older women who seem to be financially secure are at risk as they are the most likely target for elder financial abuse. Financial fraud and abuse robs elderly women of precious assets and often puts their only

asset – their home ownership - at risk. Programs like WISER's help women avoid costly mistakes and reduces the risks of exploitation and victimization by educating them on how to avoid consumer fraud, and "too good to be true" financial schemes and predatory scams.

Under The Elder Justice Act, grants are available state and community agencies to create and promote awareness programs that focus on scams, online fraud, and abuse. These services and resources are vital to America's growing elderly population, and are especially needed by older women. The problem of elder financial fraud will only increase as the population continues to age, which makes it even more critical to continue funding these and other important programs and services made possible through the Elder Justice Act.

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WRITTEN TESTIMONY OF JOHN E. MAUPIN, DDS, MBA
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ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

Friday, March 28th, 2014

SUMMARY OF FISCAL YEAR 2015 RECOMMENDATIONS:

1) **TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS:**

   - **$24.602 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**

   - **$22.133 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**

2) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH**
   - **PROVIDE PROPORTIONAL INCREASED SUPPORT FOR THE NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.**
   - **PROVIDE PROPORTIONAL INCREASED SUPPORT FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.**

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 my views before you. I am Dr. John E. Maupin, Chairman of the Board of Directors of the Association of Minority Health Professions Schools (AMHPS) and the President of the Morehouse School of Medicine. AMHPS, established in 1976, is a consortium of our nation's twelve (12) historically black medical, dental, pharmacy, and veterinary medicine schools. The members are two dental schools at Howard University and Meharry Medical College; four

colleges 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 college of veterinary medicine at Tuskegee University. 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, I speak for our institutions, when I say that the minority health professions 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, 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 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 AMHPS 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—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA)—during the Bush Administration—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.

In FY15, funding for the Title VII Health Professions Training programs must be robust, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health

(NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

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 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 FY15, I recommend a funding level of $24.602 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. ***For FY15, I recommend a funding level of $22.133 million for HCOPs.***

NATIONAL INSTITUTES OF HEALTH

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 professions 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 its Centers of Excellence program. ***For FY15, I recommend funded increases proportional with the funding of the overall NIH, with increased FTEs.***

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI), newly moved to the National Institute on Minority Health and Health Disparities 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 FY15.***

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health: Specific programs at OMH 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 has the potential to play a critical role in addressing health disparities, however that role will be greatly diminished if this agency does not retain its grant-making authority. ***For FY15, I recommend a funding level of $65 million for the OMH.***

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions: The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to AMHPS. 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 *FY15, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.***

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, AMHPS' member institutions and the Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. The Association 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.

TESTIMONY OF DAVID CARLISLE, M.D.
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PRESENTED BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

MARCH 28TH, 2014

SUMMARY OF FISCAL YEAR 2015 RECOMMENDATIONS:

1) **PROVIDE FUNDING FOR THE HEALTH RESOURCES AND SERVICES ADMINISTRATION TITLE VII HEALTH PROFESSISONS TRAINING PROGRAMS, INCLUDING:**
   - **$24.602 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE**
   - **$22.133 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**
2) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH (NIH), SPECIFICALLY:**
   - **PROPORTIONAL INCREASE FOR THE NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES (NIMHD)**
   - **PROPORTIONAL INCREASE FOR THE RESEARCH CENTERS AT MINORITY INSTITUTIONS PROGRAM**
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 FY15, the funding level for COE should be $24.602 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 FY15, the HCOP funding level of $22.133 million is recommended.***

NATIONAL INSTITUTES OF HEALTH

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 FY15, an increase proportional to NIH's increase is recommended for NIMHD as well as additional FTEs.***

Research Centers at Minority Institutions: RCMI, now at NIMHD, 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 FY15.***

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 FY15, I recommend a funding level of $65 million for OMH to support these critical activities.*** Additionally, I recommend that this Committee ensures that OMH continues with its grant-making authority, as this is one of the chief avenues by which it is able to impact the scourge of disparities in our communities.

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions: The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to CDU 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 FY15, an appropriation of $65 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 aceess 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.

TESTIMONY OF ANNA CHERIE EPPS, PH.D.
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AND
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PRESENTED BEFORE THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

SUMMARY OF FISCAL YEAR 2015 RECOMMENDATIONS:

1) **FUNDING FOR THE TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS, INCLUDING:**

   - **$24.602 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**

2) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH AND A PROPORTIONAL INCREASE FOR THE NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.**

   -PROPORTIONAL FUNDING INCREASE FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS.

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 my views before you. I am Dr. Anna Cherie Epps, President and CEO of Meharry Medical College in Nashville, Tennessee. 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. 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.

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 FY15, I recommend a funding level of $24.602 million for COEs.***

NATIONAL INSTITUTES OF HEALTH (NIH)

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 FY15, I recommend that this Institute's funding grow proportionally with the funding of the NIH and add additional FTEs.***

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI) is now housed at the National Institute on Minority Health and Health Disparities (NIMHD). RCMI 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 FY15.***

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, but this role can only be fulfilled if this agency continues it grant making authority. ***For FY15, I recommend a funding level of $65 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 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 FY15, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.***

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.

JOHN E. MAUPIN, D.D.S., MBA
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TESTIMONY
PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

Chairman Kingston, Ranking Member DeLauro, and members of the Subcommittee, my name is Dr. John E. Maupin, Jr., and I have the distinct privilege of serving as President of Morehouse School of Medicine (MSM) in Atlanta, Georgia. In addition, I am the chairman of the board of directors of the Association of Minority Health Professions Schools (AMHPS). My testimony will highlight the sources of funding which allow Morehouse School of Medicine to serve underrepresented communities and address health disparities, workforce shortages, and chronic diseases impacting vulnerable populations. The agencies and programs which I will discuss include:

- FUNDING FOR TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS, INCLUDING:
    - $24.602 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE FOR FISCAL YEAR 2014.
    - $22.133 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM FOR FISCAL YEAR 2014.
    - $33.345 MILLION FOR THE AREA HEALTH EDUCATION CENTERS FOR FISCAL YEAR 2014
- $32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH
    - $291.778 MILLION FOR THE NIH'S NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.
- $65 MILLION FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES' OFFICE OF MINORITY HEALTH.
- $65 MILLION FOR THE DEPARTMENT OF EDUCATION'S STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS PROGRAM.

I previously served as president of Meharry Medical College, executive vice-president at Morehouse School of Medicine, 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 challenges they face, especially in respect to their funding.

I want to take a moment to highlight the Historically Black Medical School's (HBMS) unique place in our society. An independent, historically black, primary health mission-centered institution like the Morehouse School of Medicine (MSM) is distinct in a world where health professionals tend to focus on more lucrative subspecialties. MSM ranks first among U.S. medical schools in terms of social mission, or the production of primary care physicians, minority doctors, and doctors practicing in underserved areas. While this conclusion might seem elementary, it is important to note that MSM was able to achieve this distinction with a graduating class of only 64. Since 1984, MSM has graduated more than 1,200 students and more than 71 percent have chosen to honor the institution's mission of serving where they are needed most: providing primary care to our underserved communities, both rural and urban.

Though the recent economic downturn has financially challenged all academic institutions, MSM and other HBMS are distinctly disadvantaged when compared to most of their peer institutions; given the societal mission, governmental and nongovernmental support finance the core curriculum and infrastructure of our institutions. Financially, MSM lacks many of the revenue streams one may find at non-minority peer institutions, including a wealthy donor base. Because MSM does so much public good, I've taken to calling us a "private institution with a public mission." For this reason and others, it is critical that federal resources, along with the private, continue to invest in MSM and the future health professionals we train.

Mr. Chairman, our mission at MSM is "to improve the health and well-being of individuals and communities; increase the diversity of the health professional and scientific workforce; and address primary health care needs through programs in education, research, and service, with emphasis on people of color and the underserved urban and rural populations in Georgia and the nation." Given this, I must point out that 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 subcommittee can help us continue to carry out our mission, 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 continues its commitment to minority health profession institutions and minority health professional training programs in order to produce the next generation of healthcare providers 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 minority patient populations 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 has 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 the experiences of students in HBMSs currently benefiting from the federal investment of HRSA funding. I know without Title VII, the impact of our institutions and the health professionals we trained, would not be. Our curriculum may not have evolved as well and our faculty recruitment would be devastated. Mr. Chairman, given the funding situation of these programs, which I see as more of an investment in the health needs of a state like Georgia, we are currently at a cross roads. This subcommittee 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.

Here are my recommendations for this subcommittee to make an investment, on which there will be a return:

HEALTH RESOURCES AND SERVICES ADMINISTATION

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 to the training of minorities in the health professions. Congress later went on to authorize the establishment of additional categories. ***For Fiscal Year (FY) 2015, I recommend a funding level of $24.602 million for COEs.*** With this level of investment, the grant authorizing agency, the Health Resources and Services Administration (HRSA), will be able to hold competition. These cycles, where the best proposal is funded, are an opportunity for MSM and similar institutions to garner the funded needed to support its mission.

Health Careers Opportunity Program—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. Lately, HCOPs have come under increased scrutiny for their efforts to reach to elementary, middle, and high schools to cultivate future health professionals. While it is true that HCOPs partner with 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, there are programs like the one MSM recently hosted which focused on undergraduates or the program which Mcharry hosted based in their post-bachelorette program. 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 FY15, I recommend a restoring of funding to $22.133 million for HCOPs.*** While I believe that there is a need to cultivate minority and underrepresented students as young as school-aged, I understand federal investment must be backed by data of efficacy. Therefore, I am open to discussing this program with authorizers to offer suggestions on its improvement.

Area Health Education Centers—AHECs are designed to encourage the establishment and maintenance of community based training programs in off-campus rural and underserved areas. At MSM, the AHEC funding focuses on exposing medical students and health professions students to primary care and practice in rural and underserved communities, with a special emphasis on primary care and interprofessional/interdisciplinary training for our health professions students. ***For FY15, I recommend $33.345 million for AHEC.***

NATIONAL INSTITUTES OF HEALTH (NIH)

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. At MSM, the Research Endowment program has been transformed our institution because it aligns with the mission of promoting minority health and health disparities research, while at the same time the building capacity component has stabilized us financially. ***For FY15, I recommend $291.778 million for NIMHD and additional full-time equivalent***

(FTE) positions. Though NIMHD has been elevated to an institute, it remains the institute with the fewest number of FTEs. Consequently, NIMHD is tasked with doing more with fewer employees to carry it out.

DEPARTMENT OF HEALTH AND HUMAN SERVICES, OFFICE OF THE SECRETARY

Office of Minority Health—OMH was created in 1986 and is one of the most significant outcomes of the landmark 1985 *Secretary's Task Force Report on Black and Minority Health.* The Office is dedicated to improving the health of racial and ethnic minority populations through the development of health policies and programs that will help eliminate health disparities. Additionally, one of the most vital roles of OMH has been its strategic grant making authority, including its cooperative agreements with MSM and other HBMS. These cooperative agreements are based on the specific needs of the communities we serve. The requirements, which are published in the Federal Register, are the agency's connection with institutions that most mirror its purpose. There are those in the Administration that do not agree with the theory that OMH should grant funding, that the agency should be solely focused on strategies. Without these cooperative agreements, OMH loses much of its most effective outreach to the communities that need it the most. The OMH has the potential to play a critical role in addressing health disparities, and with the proper funding and continued emphasis on the cooperative agreements, this role can be enhanced. ***For FY15, I recommend a funding level of $65 million for the OMH.***

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions—The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MSM and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development, initiate endowment campaigns, and support numerous other institutional development activities. While this program provides significant funding, based off a competition, institutions must match fifty cents to every dollar. ***In FY15, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.***

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 will help this country to overcome health and healthcare disparities. These investments are not only important for the health of our nation, but the elimination of health disparities will relieve our country of unnecessary health and economic burdens. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work.** 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. I welcome the opportunity to answer questions for you now or in the subcommittee's record.

WRITTEN TESTIMONY OF WANDA LIPSCOMB, Ph.D.
PRESIDENT
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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 2015 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 FY15, I recommend a funding level of $24 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 FY15, I recommend a funding level of $23 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.

WRITTEN TESTIMONY OF TSEGAYE HABTEMARIAM DVM, MPVM, PHD
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PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

Friday, March 28th, 2014

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS:

1) **TITLE VII HEALTH PROFESSIONS TRAINING PROGRAMS:**
   - **$24.602 MILLION FOR THE MINORITY CENTERS OF EXCELLENCE.**
   - **$22.133 MILLION FOR THE HEALTH CAREERS OPPORTUNITY PROGRAM.**
2) **INCREASED SUPPORT FOR THE NATIONAL INSTITUTES OF HEALTH'S NATIONAL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.**
3) **$32 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH.**
   - **PROPORTIONAL FUNDING INCREASE FOR THE NATIOANL INSTITUTE ON MINORITY HEALTH AND HEALTH DISPARITIES.**
   - **PROPORTIONAL FUNDING FOR RESEARCH CENTERS FOR MINORITY INSTITUTIONS**
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. Tsegaye Habtemariam, dean of the College of Veterinary Medicine, Nursing, and Allied Health at Tuskegee University. The mission (purpose) of Research and Advanced Studies at the College of Veterinary Medicine, Nursing & Allied Health (CVMNAH) is to transform trainees into ambassadors of the Tuskegee tradition to benefit Man and animals. Such a tradition is honed in the "one medicine-one health" concept that for decades has guided our academic mission, to expand biosciences and create bridges between veterinary medicine, agricultural and food sciences on one side and human health and welfare on the other.

Mr. Chairman, I speak for our institutions, when I say that the minority health professions 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, 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 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 Tuskegee 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—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA)—during the Bush Administration—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.

In FY15, funding for the Title VII Health Professions Training programs must be robust, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

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 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 FY15, I recommend a funding level of $24.602 million for COEs.*** Additionally, I encourage the Committee direct HRSA to re-evaluate the funding mechanism for the original four COEs, as it does not always lead to funding based on the merit of an institution's proposal.

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. ***For FY15, I recommend a funding level of $22.133 million for HCOPs.***

NATIONAL INSTITUTES OF HEALTH

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 professions 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 its Centers of Excellence program. ***For FY15, I recommend funded increases proportional with the funding of the overall NIH, with increased FTEs.***

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI), newly moved to the National Institute on Minority Health and Health Disparities 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 FY15.***

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health: Specific programs at OMH 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 has the potential to play a critical role in addressing health disparities, but that role is only possible if this agency continues to keep its grant-making authority. ***For FY15, I recommend a funding level of $65 million for the OMH.***

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions: The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to AMHPS. 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 FY15, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.**

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Tuskegee University's College of Veterinary Medicine, Nursing, and Allied Health , Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been **proven to work**. CVMNAH 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.

Testimony for the Labor, Health and Human Services Appropriations Subcommittee
U.S. House of Representatives
Kim Gandy, President and CEO, National Network to End Domestic Violence
Family Violence Prevention and Services Act (FVPSA) and related programs
March 28, 2014

Labor, Health and Human Services Appropriations Subcommittee Chairman Kingston, Ranking Member DeLauro, Chairman Rogers, Ranking Member Lowey and distinguished members of the Appropriations Committee, thank you for this opportunity to provide testimony on the importance of investing in FVPSA and VAWA programs. I sincerely thank the Committee for its ongoing support for these lifesaving programs. I am the President and CEO for the National Network to End Domestic Violence (NNEDV), the nation's leading voice on domestic violence. We represent the 56 state and territorial domestic violence coalitions, which includes over 2,000 member domestic violence and sexual assault programs, and the millions of victims they serve. Our direct connection with victims and those who serve them gives us a unique understanding of their needs and the vital importance of these continued investments. I am submitting this testimony to request a targeted investment of **$253 million** in Family Violence Prevention and Services Act (FVPSA), Violence Against Women Act (VAWA) and related programs administered by the U.S. Department of Health and Human Services in the FY 2015 Budget (specific requests below).

Incidence, Prevalence, Severity and Consequences of Domestic and Sexual Violence. The crimes of domestic and sexual violence are pervasive, insidious and life-threatening. In 2011, the Centers for Disease Control and Prevention (CDC) released the first-ever National Intimate Partner and Sexual Violence Survey, which found that domestic violence, sexual violence, and stalking are widespread. Domestic violence affects more than 12 million people each year and nearly three in ten women and one in four men have experienced rape, physical violence, or stalking in his or her lifetime. Female victims of rape, physical violence, or stalking by an intimate partner experienced severe impacts such as injury, fear, need for safe housing, concern for their safety, need for medical care, and missing work or school, and

many suffer long-term health effects. The CDC has estimated that 1,310,000 women in Georgia and 462,000 women in Connecticut alone have experienced rape, physical violence, or stalking by an intimate partner.[i] The terrifying conclusion of domestic violence is often murder, and every day in the US an average of three women are killed by a current or former intimate partner.[ii] The cycle is perpetuated as children are exposed to violence. Approximately 15.5 million children are exposed to domestic violence every year.[iii] One study found that men exposed to physical abuse, sexual abuse and adult domestic violence as children were almost four times more likely to have perpetrated domestic violence as adults.

In addition to the terrible cost of domestic and sexual violence to individual victims and their families, these crimes cost taxpayers and communities. Based on 1999 CDC figures, the cost of intimate partner violence exceeds $5.8 billion each year, $4.1 billion of which is for direct health care services.[iv] Translating this into 2012 dollars, based on share of GDP, the annual cost to the nation is over $9 billion per year, more than two-thirds of which is for direct health care services. In addition, domestic violence costs U.S. employers an estimated $3 to $13 billion annually.[v]

Despite this grim reality, we know that when a coordinated response is developed and immediate, essential services are available, victims can escape from life-threatening violence and begin to rebuild their lives. To address unmet needs and build upon their successes, FVPSA and VAWA programs should receive significant increases in the FY '15 Labor, Health and Human Services Appropriations bill.

Family Violence Prevention and Services Act (FVPSA) [ACF] – $175 million request. Since its passage in 1984, FVPSA has remained the only direct federal funding for shelter programs. Now in its 30th year, FVPSA has contributed to substantial progress toward ending domestic violence. Despite the progress brought about by FVPSA, an unconscionable need remains for FVPSA-funded victim services.

Through state formula grants, FVPSA helps to fund approximately 1,500 community-based domestic violence programs helping victims and their children attain safety and independence. These programs offer services such as emergency shelter, counseling, legal assistance, and preventative education to millions of

adults and children every year, and are at the heart of our nation's response to domestic violence. A recent multi-state study conclusively shows that the nation's domestic violence shelters are addressing victims' urgent and long-term needs and are helping victims protect themselves and their children. This same study concluded that, if shelters did not exist, the consequences for victims would be dire, including "homelessness, serious losses including children [or] continued abuse or death."[vi] Additionally, non-residential domestic violence services are essential – such as counseling, child care, job assistance, help with budgeting and finances, and safety planning. Without the services she received from her local domestic violence program, one victim said, "I would not be alive, I'm 100 percent certain about that."[vii]

The Need for Increased Funding: to Maintain Programs and Bridge the Gap. Many programs across the country use their FVPSA funding to keep the lights on and their doors open. We cannot overstate how important this is: victims must have a place to flee when they are escaping life-threatening violence. As increased training for law enforcement, prosecutors and court officials has improved the response to victims of domestic violence, there has been an increase in demand for emergency shelter, hotlines and supportive services. Additionally, demand has increased since the economic downturn, and victims with fewer personal resources have become increasingly vulnerable. Since the economic crisis began, shelters have reported an increase in women seeking to escape and recover from abuse. As a result, shelters overwhelmingly report that they cannot fill the growing need for their services.

At a Congressional briefing earlier this month, NNEDV released Domestic Violence Counts, a 24-hr **national snapshot of domestic violence services (the Census)**. The report revealed that in just one day in 2013, while more than 66,000 victims of domestic violence received services, over 9,640 requests for services went unmet, due to lack of funding and resources. Of those unmet requests, 60% were for safe housing. In 2013, domestic violence programs laid off nearly 1,700 staff positions including counselors, advocates and children's advocates, and also had to reduce or completely eliminate over 1,280 services

including emergency shelter, legal advocacy, and counseling. I strongly encourage you to read NNEDV's DV Counts 2013 Census at www.nnedv.org/census2013 to learn more.

In 2011, domestic violence programs funded by the Family Violence Prevention & Services Act (FVPSA) provided shelter and nonresidential services to more than one million victims. However, due to lack of capacity, an additional 170,069 requests for shelter went unmet. Furthermore, because of sequestration approximately 70,120 fewer victims had access to FVPSA-funded domestic violence programs and shelters last year. In FY 2013, Georgia's 46 state-certified domestic violence programs sheltered 7,807 victims, providing 248,463 bed-nights of shelter. However, due to lack of available bed-space, domestic violence shelters were forced to turn away approximately 4,612 victims and their children. Since 2011, at least 19 local domestic violence programs across the country have been forced to close entirely.

For those individuals who are not able to find safety, the consequences can be dire, including continued exposure to life-threatening violence or homelessness, or it can be deadly. It is absolutely unconscionable that victims cannot find safety for themselves and their children due to a lack of adequate investment in these services. In order to meet the immediate needs of victims in danger and to continue to prevent and end domestic violence, FVPSA funding must be increased to its authorized amount of $175 million.

ADDITIONAL REQUESTS

National Domestic Violence Hotline [ACF] – $5 million. For the past 20 years the Hotline has provided 24-hour, toll-free and confidential services, immediately connecting callers to local service providers. Crisis calls to the Hotline have increased during the economic downturn.

DELTA Prevention Program [CDC] – $6 million. DELTA is one of the only sources of funding for domestic violence prevention, supporting statewide projects that integrate primary prevention principles and practices into local coordinated community responses, to address and reduce the incidence of domestic violence. Currently, DELTA funds 56 Coordinated Community Response Coalitions nationwide. In the first three years of DELTA funding, primary prevention activities in these communities increased ten-fold.

Rape Prevention and Education (RPE) [CDC] – $50 million. This VAWA state formula grant program administered through CDC strengthens national, state and local sexual violence prevention efforts and the operation of rape crisis hotlines, through formula grants to states and territories. Despite its critical work, RPE has faced funding decreases since FY '06.

Preventative Health and Health Services Block Grant (PHHSBG)– The Rape Set-Aside ($7 million) administered by the CDC allows states, territories and tribes to address their own unique public health needs. The 2010 Public Health Service Act included a guaranteed $7 million minimum set-aside to support direct services to victims of sexual assault and to prevent rape. Rape crisis centers depend on this funding to provide direct services, operate hotlines and offer prevention programs.

VAW Health – (Office of Women's Health) – $10 million. This program supports work to increase screening and referrals for victims in a healthcare setting.

Conclusion

Together, these LHHS programs work to prevent and end domestic and sexual violence. While our country has made continued investments in the criminal justice response to these heinous crimes, we need an equal investment in the human service, public health and prevention responses in order to holistically address and end the violence. These vital, cost-effective programs help break the cycle, reduce related social ills, and will save our nation money now and in the future

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[i] Black, M.C., Basile, K.C., Breiding, M.J., Smith, S.G., Walters, M.L., Merrick, M.T., Chen, J., & Stevens, M.R. (2011). The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Summary Report. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.

[ii] Bureau of Justice Statistics (2008). Homicide Trends in the U.S. from 1976-2005. U.S. Dept. of Justice.

[iii] McDonald, R., et al. (2006). "Estimating the Number of American Children Living in Partner-Violence Families." *Journal of Family Psychology, 30(1)*, 137-142.

[iv] National Center for Injury Prevention and Control. *Costs of Intimate Partner Violence Against Women in the United States.* Atlanta (GA): Centers for Disease Control and Prevention; 2003.

[v] Bureau of National Affairs Special Rep. No. 32, Violence and Stress: The Work/Family Connection 2 (1990); Joan Zorza, *Women Battering: High Costs and the State of the Law*, Clearinghouse Rev., Vol. 28, No. 4, 383, 385.

[vi] Lyon, E. & Lane, S. (2009). Meeting survivors' needs: A multi-state study of domestic violence shelter experiences. Harrisburg, PA: National Resources Center on Domestic Violence.

[vii] Lyon, Eleanor, Bradshaw, Jill, Menard, Anne. *Meeting Survivors' Needs through Non-Residential Services & Supports: Results of a Multi-State Study*. Harrisburg, PA: National Resource Center on Domestic Violence. November, 2011.

Testimony of the American Public Health Association submitted for the record
Georges Benjamin, MD, Executive Director
Concerning the fiscal year 2015 budgets for CDC and HRSA
House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies
March 28, 2014

The American Public Health Association is a diverse community of public health professionals who champion the health of all people and communities. We are pleased to submit our request to fund the Centers for Disease Control and Prevention at $7.8 billion and the Health Resources and Services Administration at $7.48 billion in FY 2015. We urge you to take our recommendations to restore funding to at least FY 2010 levels into consideration as you move forward with writing the FY 2015 Labor-HHS-Education Appropriations bill.

Centers for Disease Control and Prevention

APHA believes Congress should support CDC as an agency, not just the individual programs that it funds. Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, **we urge a funding level of $7.8 billion for CDC's programs in FY 2015.** We appreciate some of the important new investments in President Obama's FY 2015 budget proposal; however, under the president's proposal, CDC's total budget would be cut by nearly $243 million compared to FY 2014. CDC's budget authority under the president's budget is lower than FY 2003 levels. State and local health departments continue to operate on tight budgets and with a smaller workforce, losing more than 50,000 public health jobs since 2008. These cuts will reduce the ability of CDC and its state and local grantees to investigate and respond to public health emergencies, ensure adequate immunization rates and track environmental hazards.

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By translating research findings into effective intervention efforts, CDC is a critical 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. It is notable that more than 70 percent of CDC's budget supports public health and prevention activities by state and local health organizations and agencies, national public health partners and academic institutions.

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 and the many other natural and man-made threats that exist in the modern world, 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 erisis or outbreak.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs 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. Unfortunately, this is not a threat that is going away.

CDC plays a significant role in addressing chronic diseases such as heart disease, stroke, cancer, diabetes and arthritis that continue to be the leading causes of death and disability in the United States. These diseases, many of which are preventable, are also among the most costly to our health system. CDC's National Center for Chronic Disease Prevention and Health Promotion provides critical funding for state programs to prevent chronic disease, conducts

surveillance to collect data on disease prevalence and monitor intervention efforts and translates scientific findings into public health practice in our communities.

CDC's National Center for Environmental Health is essential to protecting the health and well being of the public by helping to control asthma, protect from threats associated with climate change and reduce exposure to lead and other hazards. We urge the subcommittee to provide adequate funding for NCEH which has been significantly cut in recent years.

Health Resources and Services Administration

HRSA operates programs in every state and U.S. territory and is a national leader in improving the health of Americans through the delivery of quality health services and supporting a well prepared workforce. The agency serves the health needs of people who are medically vulnerable, low-income and geographically isolated. The nation faces a shortage of health professionals and continues to experience an ever growing, aging and increasingly diverse population, alongside health professionals that are nearing retirement age. We are deeply concerned that since FY 2010, HRSA's discretionary budget authority has been cut by 19 percent in nominal dollars and 25 percent when adjusted for inflation. Funding for HRSA is far too low and keeping austerity measures in place will threaten the agency's ability to address the present and growing health needs of the U.S. To respond to the needs of our nation, **APHA recommends restoring funding to the FY 2010 level of $7.48 billion for discretionary HRSA programs in FY 2015.**

HRSA programs have a strong history of providing quality care to keep people healthy and improve health equity for those living outside of the economic and medical mainstream. HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the nation's health, which is now at an all-time low. Most recently, preliminary data indicates that the infant mortality rate for black infants has decreased, resulting in a narrowing of the gap that exists between racial groups. HIV/AIDS programs administered by HRSA provide access to

regular care and ensure adherence to antiretroviral treatment for people living with HIV, which reduces HIV transmission by 96 percent and greatly contributes to the prevention of new HIV infections. A committed investment from Congress is required to continue achieving the health improvements HRSA has made and to pave the way for new achievements.

Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs, including:

- Health Professions supports the education and training of a broad range of health professionals. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so health professionals are well-equipped to care for the growing and changing population.
- Primary Care supports 9,200 health sites in every state and U.S. territory, improving access to care for more than 21 million patients in geographically isolated and economically distressed communities. Close to half of these health centers serve rural populations. In addition, health centers target populations with special needs, including migrant and seasonal farm workers, homeless individuals and families and those living in public housing.
- Maternal and Child Health including the Title V Maternal and Child Health Block Grant, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality health care for more than 43 million women and children, including children with special health care needs.
- HIV/AIDS provides assistance to states and communities most severely affected by HIV/AIDS. The programs deliver comprehensive care, prescription drug assistance and support services for about half of the total population – 1.1 million people – living with

HIV/AIDS in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.

- Family Planning Title X services ensure access to a broad range of reproductive, sexual and related preventive health care for over 5 million poor and low-income women, men and adolescents at nearly 4,400 health centers nationwide. This program helps improve maternal and child health outcomes and promotes healthy families.
- Rural Health improves access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of health care services. These 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.

Conclusion

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up less than one percent of federal spending and continued austerity measures that cut funding for public health and prevention programs will not balance our budget and will only lead to increased costs to our health care system. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes and other population-based interventions that are effective and available for everyone. Without a robust and sustained investment in our public health agencies, we will fail to meet the mounting health challenges facing our nation.

Testimony of the National Nursing Centers Consortium Regarding

Fiscal Year 2015 Appropriations for the Nurse-Managed Health Clinic Grant Program

U.S. House Appropriations Subcommittee on Labor, Health and Human Services,

Education, and Related Agencies

Department of Health and Human Services

March 28, 2014

Submitted for the record by Tine Hansen-Turton, NNCC CEO

On behalf of the National Nursing Centers Consortium (NNCC), I would like to thank the members of this subcommittee for the opportunity to submit testimony regarding the importance of appropriating funds to support nurse-managed health clinics. Specifically, NNCC and its members request an appropriation of $20 million to support grants to nurse-managed health clinics through the Nurse Managed Health Clinic grant program under the Health Resources and Services Administration's Bureau of Primary Health Care in the Department of Health and Human Services.

NNCC is a 501(c)(3) member association of nonprofit, nurse-managed health clinics, sometimes called nurse-managed health centers or NMHCs. Section 254(c)-1a(a)(2) of the Public Health Services Act defines "nurse-managed health clinic" as "a nurse practice arrangement, managed by advanced practice nurses, that provides primary care or wellness services to underserved or vulnerable populations and that is associated with a school, college, university or department of

nursing, federally qualified health center (FQHC), or independent nonprofit health or social services agency." Currently, there are approximately 250 NMHCs in operation throughout the United States. Section 254(c)-1a also mandates the creation of a Nurse Managed Health Clinic grant program and authorizes $50 million in grant funding.[i] The NMHC grant program was established to provide these clinics with a stable source of federal funding that would place them on footing similar to other safety-net providers. However, to date, funding for the grant program has not been appropriated.

The Value of NMHCs and the Need for NMHC Grant Funding

NMHCs Expand Primary Care Workforce Capacity - The nation is facing a primary care crisis that is about to get worse. According to the Association of American Medical Colleges (AAMC), by 2025 there will be a dearth of 130,600 physicians, which includes a shortage of 65,800 primary care physicians.[ii] AAMC data also shows that American medical schools are not graduating enough doctors to meet this need.[iii] The Congressional Budget Office estimates the Medicaid expansion called for by the ACA will lead to 11 million new enrollees.[iv] As these new enrollees establish primary care homes, the burden on the primary care workforce is likely to increase dramatically.

Data from Massachusetts shows just how bad the problem could get. A study conducted two years after expanding its public coverage found that only 52% of internists in Massachusetts were accepting new patients and one-third of family physicians were no longer accepting new patients.[v]

NMHCs are primarily managed by nurse practitioners, which make up the fastest growing segment of primary care providers in the country. According to the Health Resources and Services Agency, the number of primary care NPs is expected to grow by 30%, from 55,400 in 2010 to 72,100 by 2020.[vi] Because of these growing numbers, policymakers across the country are calling for nurse practitioners and NMHCs to assume a greater role in primary care. For example, in its report, "The Future of Nursing, Leading Change, Advancing Health," the Institute of Medicine (IOM) states, "advanced practice registered nurses should be called upon to fulfill and expand their potential as

primary care providers across practice settings based on their education and competency."[vii] When discussing the role of NMHCs, the IOM report says, "Nurse-managed health clinics offer opportunities to expand access; provide quality, evidence-based care; and improve outcomes for individuals who may not otherwise receive needed care."[viii]

Along with the IOM, the National Governor's Association (NGA) and the National Institute for Health Care Reform (NIHCR) both released reports identifying the greater use of nurse practitioners as a means of alleviating the pressure on the primary care workforce and presenting NP scope of practice law and payment policy reform as important to ensuring comprehensive access to primary care. Most recently, in a 2013 study published in Health Affairs, the RAND Corporation projected that greater use of the nurse-managed health centers model could address the increased demand for primary care.[ix]

As safety-net providers, NMHCs offer high quality primary care to medically underserved patients regardless of the patient's ability to pay. However, NMHCs are struggling financially and often lack access to FQHC money available to other safety net providers. Thus, the NMHC grant program was created, providing NMHCs with alternative federal funding to ensure their continued ability to meet the needs of their patients and communities. Because they already serve a high percentage of Medicaid patients, the clinics are positioned to not only absorb demand from the newly ensured but also fill gaps in care resulting from the fragmented application of Medicaid expansion.

To lessen the primary care crisis and ensure the underserved can take full advantage of the care NMHCs offer, NNCC requests that the Subcommittee appropriate funding to the NMHC grant program. Evidence suggests that funding NMHCs will not only expand access but also lower the cost of care. In addition to lower labor costs, research shows that NMHCs decrease costs by reducing unnecessary emergency room visits and hospitalizations.[x]

NMHCs Help Educate the Health Professionals of Tomorrow – FQHC funding is often unavailable to NMHCs, because many are affiliated with academic schools of nursing. Academically-affiliated NMHCs operate under the jurisdiction of a university, so most cannot meet FQHC governance requirements without breaking their academic connection and giving up their clinical programs. Ironically, it is these academic affiliations that make the NMHC model especially responsive to primary care shortages, since they contribute to workforce development. NMHCs naturally serve as community-based clinical training sites for a diverse group of health profession students including those training to be registered nurses and advance practice nurses (mostly nurse practitioners) as well as medical, pharmacy, dental, social work, public health, and other students. In post-clinical focus groups, students report being "overwhelmingly satisfied" with their experience in NMHC clinical rotations, crediting, in part, the community-based experience absent from other clinical rotations.[xi] The Future of Nursing report also praised NMHC clinical programs for their interprofessional education, which relates to both job satisfaction and a flexible workforce.[xii]

In 2012, the NNCC conducted a survey of its members to measure their contribution to health professions education. Twenty-eight NMHCs in a mix of urban, rural, and suburban communities reported providing educational opportunities for nearly 1,500 students.[xiii] The average number of students educated by the NMHC grant funded clinics was 80, while the clinics participating in the 2012 survey reported educating an average of 55 students. These results demonstrate that (1) NMHCs advance workforce development and (2) increased funding enhances the ability of NMHCs to offer educational opportunities.

Despite the benefits of NMHC clinical programs, NMHC leaders are often forced to abandon this important piece of the NMHC model to qualify for FQHC funding. By providing an alternative source of funding for NMHCs, the Nurse-Managed Health Clinic grant program helps to preserve the contribution of NMHCs to workforce development. Given the country's growing need for

nurses, NNCC respectfully requests that the subcommittee members appropriate funding to support clinical programs and place NMHCs on a similar footing with other safety-net providers through the NMHC grant program.

In October of 2010, HRSA released $14.8 million in Prevention and Public Health Fund dollars to fund ten NMHC grants. In addition to serving over 27,000 patients and recording more than 72,000 encounters, the NMHC grantees have provided interdisciplinary clinical training to over 800 health profession students annually.[xiv]

Request - The 10 NMHC grants distributed in 2010 will expire this year if Congress does not move to appropriate funding to the program. NNCC respectfully requests an appropriation of $20 million in fiscal year 2015 for the Nurse-Managed Health Clinic Grant Program, as authorized under Title III of the Public Health Service Act.

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[xiv] National Nursing Centers Consortium (NNCC). (2011). Survey of NMHCs.

Friends of the Health Resources and Services Administration
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Nicole Burda, Government Relations Deputy Director
Testimony of the Friends of the Health Resources and Services Administration
House Appropriations Subcommittee on Labor, HHS, Education and Related Agencies
March 28, 2014

The Friends of HRSA is a non-partisan coalition of more than 170 national organizations representing millions of public health and health care professionals, academicians and consumers invested in HRSA's mission to improve health and achieve health equity. For FY 2015, we recommend restoring HRSA's discretionary budget authority to the FY 2010 level of $7.48 billion. We are deeply concerned that since FY 2010, HRSA's discretionary budget authority has been cut by 19 percent in nominal dollars and 25 percent when adjusted for inflation. Funding for HRSA is far too low and keeping austerity measures in place will threaten the agency's ability to address the present and growing health needs of the U.S. Of additional concern, cuts will be compounded by the fact that multiple mandatory programs are set to expire soon, which account for nearly one-third of HRSA's total program level. In the absence of continued mandatory funding for the Maternal, Infant, and Early Childhood Home Visiting Program, National Health Service Corps Fund and Community Health Center Fund, the committee will be faced with addressing these shortfalls in the Labor-HHS-Education appropriations bill.

The nation faces a shortage of health professionals and continues to experience an ever growing, aging and increasingly diverse population, alongside health professionals that are nearing retirement age. Additionally, national estimates of workforce shortages are often masked by significant distributional disparities – particularly in rural and certain inner-city populations

that experience greater shortages. By restoring funding to HRSA, the agency will be able to more effectively fill the primary and preventive care gaps for people living outside of the medical and economic mainstream through supporting a well prepared workforce and high-quality health services.

HRSA operates programs in every state and U.S. territory and is a national leader in improving the health of Americans. HRSA programs have reduced AIDS-related deaths through providing drug treatment regimens for people living with HIV and have the potential to prevent the spread of HIV by 96 percent by ensuring that people living with HIV have access to regular care and adhere to their antiretroviral medications. Less than 10 percent of people who experience a cardiac arrest outside of a hospital setting survive. HRSA provides rural communities with training and access to emergency devices which can more than double a patient's chance of survival. HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the nation's health, which is now at an all-time low. Most recently, preliminary data indicates that the infant mortality rate for black infants has decreased, resulting in a narrowing of the gap that exists between racial groups.

Now is the time to make a strong investment in a robust workforce and to improve access to care to continue achieving the health improvements HRSA has made and to pave the way for new achievements. The nation only stands to benefit from a healthier population through a thriving workforce and reduced health care costs. Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs including:

- Health professions programs support the education and training of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health

professionals, pharmacists and other allied health providers. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so health professionals are well-equipped to care for the nation's growing, aging and increasingly diverse population. Additionally, HRSA provides interdisciplinary training to health professionals to accurately screen, diagnose and treat children with autism and other developmental disabilities.

- Primary care programs support nearly 9,200 service delivery sites in every state and territory, improving access to preventive and primary care to more than 21 million patients in geographically isolated and economically distressed communities. Close to half of the health centers serve rural populations. The health centers coordinate a full spectrum of health services including medical, dental, behavioral and social services – often delivering the range of services in one location. In addition, health centers target populations with special needs, including agricultural workers, homeless individuals and families and those living in public housing. Following health insurance reform in Massachusetts, health centers experienced a substantial increase in newly-insured patients. We expect the same will be true nationally, as health insurance expands to millions of Americans who were previously uninsured. Health centers and other programs administered by HRSA will remain vital sources of care for patients and continue to reduce costs to the health system.

- Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality health care for 43 million women and children. MCH programs help assure that nearly all

babies born in the U.S. are screened for a range of serious genetic or metabolic diseases and that a community-based system of family centered services is available for coordinated long-term follow up for babies with a positive screen and for all children with special health care needs.

- HIV/AIDS programs provide the largest source of federal discretionary funding assistance to states and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance and support services for more than half a million low-income people impacted by HIV/AIDS, which accounts for about half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.
- Family planning Title X services ensure access to a broad range of reproductive, sexual and related preventive health care for over 5 million poor and low-income women, men and adolescents at nearly 4,400 health centers nationwide. Health care services include patient education and counseling, cervical and breast cancer screening, sexually transmitted disease prevention education, testing and referral, as well as pregnancy diagnosis and counseling. This program helps improve maternal and child health outcomes and promotes healthy families. Often, Title X service sites provide the only continuing source of health care and education for many individuals.
- Rural health programs improve access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of health care services. The Office of Rural Health Policy serves as the nation's primary voice for programs and research on rural health issues. 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. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Special programs also include the Poison Control Program, the nation's primary defense against injury and death from poisoning. For every dollar spent on the poison center system, $13.39 is saved in medical costs and lost productivity, totaling more than $1.8 billion every year in savings.

While the Bipartisan Budget Act of 2013 and Consolidated Appropriations Act of 2014 provided modest and temporary relief from sequestration, austerity measures remain firmly in place, which pose serious threats for the viability of HRSA's important programs and compromise the agency's ability to address our nation's health needs. We urge you to consider HRSA's central role in strengthening the nation's health and advise you to adopt our FY 2015 request of $7.48 billion for HRSA's discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

Outside Witness Testimony for the Record
Subcommittee on Labor, Health and Human Services, Education and Related Agencies Appropriations Committee

United States House of Representatives
March 28, 2014
Kaitlin Christenson, Director, Global Health Technologies Coalition

National Institutes of Health and Centers for Disease Control and Prevention FY 2015 Appropriations

Chairman Kingston, Ranking Member DeLauro, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year (FY) 2015 appropriations funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). We appreciate your leadership in promoting the importance of international development, in particular global health. We hope that your support will continue. I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of nearly 30 nonprofit organizations working together to promote policies that advance research and development (R&D) of new global health innovations–including new vaccines, drugs, diagnostics, microbicides, and other tools–to combat global health diseases. The GHTC's members strongly believe that to meet the global health needs of tomorrow, it is critical to invest in research today so that the most effective health solutions are available when we need them. My testimony reflects the needs expressed by our member organizations which work with a wide variety of partners to develop new and more effective life-saving technologies for the world's most pressing health issues. **We strongly urge the Committee to continue its established support for global health R&D by 1) sustaining and supporting US investment in global health research and product development and fully funding the NIH at a level of at least $32 billion, and providing robust funding for the CDC, with $464 million for the CDC Center for Global Health and $445 million for the CDC Center for Emerging Zoonotic and Infectious Diseases (NCEZID), 2) requiring leaders at the NIH, CDC, the Food and Drug Administration (FDA), and the Secretariat of the US Department of Health and Human Services to join leaders of other US agencies to develop a cross-US government global health R&D strategy to ensure that US investments in global health research are efficient, coordinated, and streamlined,**

and 3) removing the clinical trial phase restriction from the legal language dictating the activities of the National Center for Advancing Translational Sciences (NCATS).

Critical need for new global health tools

Our nation's investments have made historic strides in promoting better health around the world: nearly ten million people living with HIV/AIDS now have access to life-saving medicines; new, cost-effective tools help us diagnose diseases quicker and more efficiently than ever before; and innovative new vaccines are making significant dents in childhood mortality. While we must increase access to these and other proven, existing health tools to tackle global health problems, it is just as critical that we continue to invest in developing the next generation of tools to stamp out disease and address current and emerging threats. For instance, newer, more robust, and easier to use antiretroviral drugs—particularly for infants and young children—are needed to treat and prevent HIV, and even an AIDS vaccine that is 50 percent effective has the potential to prevent one million HIV infections every year. Drug-resistant tuberculosis (TB) is on the rise globally, including in the United States, however the only vaccine on the market is insufficient at 90 years old, and most therapies available today are more than 50 years old, extremely toxic, and too expensive. New tools are also urgently needed to address fatal neglected tropical diseases (NTDs) such as sleeping sickness, for which diagnostic tools are inadequate and the few drugs available are toxic or difficult to use. There are many very promising technology candidates in the R&D pipeline to address these and other health issues; however, these tools will never be available if the support needed to continue R&D is not supported and sustained.

Research and US global health efforts

The United States is at the forefront of innovation in global health technologies. The US government is involved in 200 of the 365 global health products currently in the pipeline, with the NIH and CDC involved in much of this research.

NIH

The NIH has helped make the United States a leader in research globally. Dr. Francis Collins, director of the NIH, has named global health as one of the agency's five top priorities, and recent NIH global health research activities helped lead to the development of the first-ever microbicide gel effective in preventing HIV/AIDS and the development of new tools to combat neglected diseases, including vaccines for dengue fever and trachoma, as well as new drugs to treat malaria and TB.

Under the purview of the NIH, NCATS was established to accelerate new treatments and cures for diseases. NCATS has the potential to play a much needed role in global health research, but we remain concerned about the legislative mandate limiting NCATS in their clinical trial work. NCATS is the only NIH center to be limited by a legislative mandate in its clinical trial work. There is no risk of NCATS duplicating the global health activities of private industry as this sector does not typically target neglected diseases due to small commercial markets. We hope you will consider removing this statutory barrier. We must not lose traction on the investments made in global health at NIH. Robust investment is needed to ensure that new global health tools are available to address current and future health challenges.

CDC

The CDC also plays a critical role in global health and contributes to valuable surveillance and health research systems—strengthening programs that ensure the sustainability of global health R&D. The work of its scientists has led to major advancements against devastating diseases, including the eradication of smallpox and early identification of the disease that became known as AIDS. Within the CDC, the efforts of the Center for Global Health and NCEZID are critical to protecting lives and must be continued. Ongoing investments in the development of new vaccines, drugs, microbicides and other tools have the potential to greatly accelerate efforts to combat HIV/AIDS, TB, malaria, diarrheal disease, pneumonia, and other less well known diseases such as leishmaniasis, dengue fever, schistomiasis, hookworm, sleeping sickness, and Chagas disease, as well as help prevent maternal and reproductive health challenges.

Leveraging the private sector for innovation

The NIH, CDC, and other US agencies involved in global health R&D regularly collaborate with the private sector in developing, manufacturing, and introducing important technologies such as those described above through public-private partnerships, including product development partnerships. These partnerships leverage public-sector expertise in developing new tools, partnering with academia, large pharmaceutical companies, the biotechnology industry, and governments in developing countries to drive greater development of products for neglected diseases in which private industries have not historically invested. This unique model has generated 42 new global health products and has enormous potential for continued success if robustly supported. NIH Director Francis Collins has stated that such partnership is key to the development of therapies and health tools based on NIH-funded research.

Innovation as a smart economic choice

Global health R&D brings life-saving tools to those who need them most. However, the benefits these efforts bring are much broader than preventing and treating disease. Global health R&D is also a smart economic investment in the United States, where it drives job creation, spurs business activity, and benefits academic institutions. Biomedical research, including global health, is a $100 billion enterprise in the United States. Sixty-four cents out of every US dollar invested in global health R&D goes directly to US-based researchers. In a time of global financial uncertainty, it is important that the United States support industries, such as global health R&D, which build the economy at home and abroad.

An investment made today can help save significant money in the future. The recently released meningitis A vaccine, MenAfriVac, is on course to save nearly $570 million in health care costs over the next decade. In addition, new therapies to treat drug-resistant TB have the potential to reduce the price of TB treatment by 90 percent and cut health system costs significantly. The United States has made smart investments in research in the past that have resulted in lifesaving breakthroughs for global health diseases, as well as

important advances in diseases endemic to the United States. We must now build on those investments to turn those discoveries into new vaccines, drugs, tests, and other tools.

Recommendations

In this time of fiscal constraint, support for global health research that improves the lives of people around the world–while at the same time creating jobs and spurring economic growth at home–should unquestionably be among the nation's highest priorities. In keeping with this value, the GHTC respectfully requests that the Committee do the following: 1) sustain and support US investments in global health research and product development and fully fund the NIH at a level of at least $32 billion, and provide robust funding for the CDC, with $464 million for the CDC Center for Global Health and $445 million for the NCEZID, 2) require leaders at the NIH, CDC, the FDA and the Office of Global Affairs to collaborate with the US Agency for International Development, the State Department, the Department of Defense, and Office of the US Global AIDS Coordinator to develop a cross-US government global health R&D strategy to ensure that US investments in global health research are efficient, coordinated, and streamlined, and 3) remove current statutory and legislative barriers limiting NCATS' clinical trial mandate and require NCATS to develop and report on a plan to include initiatives targeted at neglected diseases and global health conditions. As a leader in science and technology, the United States has the ability to capitalize upon our strengths to help reduce illness and death and ultimately eliminate disabling and fatal diseases for people worldwide, contributing to a healthier world and a more stable global economy. Sustained investments in global health research to develop new drugs, vaccines, tests, and other health tools–combined with better access to existing methods to prevent and treat disease–present the United States with an opportunity to dramatically alter the course of global health while building political and economic security across the globe. On behalf of the members of the GHTC, I would like to extend my gratitude to the Committee for the opportunity to submit written testimony for the record.

U.S. House Labor, HHS, and Education Appropriations Subcommittee
Statement Submitted for the Record by
Jim Gibbons, President and CEO
Goodwill Industries International
March 25, 2014

Mr. Chairman, Ranking Member, and Members of the Committee, on behalf of Goodwill Industries International® (GII), I appreciate this opportunity to submit this written statement on the FY 2015 Labor, Health and Human Services, and Education Appropriations bill.

For more than 110 years Goodwill agencies have provided people with the skills they need to live better lives. Now more than ever, with unemployment slowly declining from the highest levels experienced in a generation, local Goodwill agencies are on the front lines of the economic recovery assisting people with employment barriers, including the following.

- Individuals with disabilities
- Older workers,
- Families on Temporary Assistance to Needy Families (TANF)
- Veterans and wounded warriors
- People who were incarcerated

In 2013, Goodwill raised approximately $5 billion in its 2,900 retail stores and other social enterprises, and invested more than 82 percent of its privately-raised revenues to supplement federal investments in programs that give people the skills they need to find jobs and advance in careers. Goodwill provided job training, employment services, and supportive services to approximately 10 million people, placing nearly 230,000 people in jobs and employing nearly 120,000.

Goodwill is proud of these and other achievements. They are truly the result of a public-private partnership. As the recovery from the worst recession since the Great Depression continues and unemployment rates slowly decline from near 10 percent, Goodwill Industries believes it is wise to continue to invest in proven strategies that build upon and leverage existing resources that will address the employment needs of our nation.

Goodwill appreciates Congress's efforts to address our nation's debt and the deficit through the two-year Bipartisan Budget Act adopted on December 10, 2013. This budget agreement maintains the progress made to reduce the deficit, yet gives Congress the flexibility to meet our nation's most pressing needs. Support for our nation's workforce is among those needs. Unfortunately, over the past several years, funding for a number of Goodwill's funding priorities, targeted at employment and job training, has declined significantly, therefore stretching resources critically thin.

While local Goodwill agencies care about a range of federal funding sources, Goodwill urges appropriators to demonstrate that employment and training programs are a top priority by providing adequate funding for the Workforce Investment Act's adult, dislocated worker, and youth funding streams; Community College Partnerships; and the Senior Community Service Employment Program (SCSEP).

Workforce Investment Act

Funding for the Workforce Investment Act's youth, adult, dislocated worker formulas is one of Goodwill's top funding priorities for FY 2015. The U.S. Department of Labor estimates that WIA's three core funding streams will assist more than 5.2 million people this year to find jobs, and access education and training that aims to improve their future employment prospects.

Goodwill is doing all it can to supplement the federal investment in job training, employment services, and other supports for people who are trying to find jobs and advance in careers. WIA funds support

many agencies' efforts to provide skills training, job placement and job retention services to people with employment challenges, including people with disabilities, people who receive welfare, and other job seekers. In addition, several agencies are one-stop lead operators or operators in association with other service providers. Many agencies are also active on state and local workforce boards, and most Goodwill agencies have people referred to them through the workforce system.

The Administration's FY 2015 budget proposes approximately $2.7 billion for WIA's three main funding streams, and an additional $60 million to pay the U.S. Department of Labor's portion of a Workforce Innovation Fund to "support and test promising approaches to training, and breaking down program silos, building evidence about effective practices, and investing in what works." Goodwill believes that a Workforce Innovation Fund is a promising idea, is very interested in the details, and is encouraged by the Administration's efforts to increase interagency collaborations and leverage resources provided by community-based organizations.

Goodwill has been very be alarmed by the steady erosion of funding for WIA's adult, youth, and dislocated worker funding streams. In 2002, when the unemployment rate was 5.8 percent, combined funding for WIA's youth, adult, dislocated worker, and funding streams was more than $3.67 billion. More than ten years later, combined FY 2013 funding for WIA's core funding streams and the Workforce Innovation Fund was $2.47 billion – more than $1.2 billion, or 33 percent, less than in 2002 – yet at a time when job training is more in demand than ever before.

Therefore, Goodwill was very pleased that Congress reversed the decade-long erosion of funding for WIA job training programs with $121 million in additional resources for FY 2014. Goodwill urges Congress to again show support for WIA's adult, youth, and dislocated worker funding streams by matching the FY 2014 increase in FY 2015 to provide a combined funding level of at least $2.71 billion. In addition, Goodwill supports the Administration's proposal to increase funding for the Workforce Innovation Fund to $60 million for FY 2015.

Furthermore, Goodwill is very interested in the Administration's Opportunity, Growth, and Security Initiative (OGSI). OGSI includes funding for the Community College Job-Driven Training Fund, funding to restore prior cuts in job training and employment services, increased investments for innovation, and targeted resources for populations that face significant barriers to employment. In addition, Goodwill applauds the Administration for including funding the New Careers Pathway Program and Job Driven Training for Youth and Long Term Unemployed.

Finally, as a service provider and employer of many individuals with significant disabilities, Goodwill also supports the Administration's proposal for $899,000 and 7 full time equivalents to promote increased compliance with FLSA Section 14(c) . This provision in FLSA authorizes employers to pay special minimum wages. Resources should be devoted to allow for more investigators and training in order to avoid misuse of the special minimum wage certificate.

Community College Partnerships

Goodwill continues to hear employers express that it remains difficult to find workers that have the skills that employers seek. In response, Goodwill launched the Community College/Career Collaboration (C4) in 2009 to enhance local agencies' collaboration with community colleges to combine their assets and resources to provide easy access to education, job training and other supportive services to individuals who lack a college or career credential that employers look for. To date, more than 70 local Goodwill agencies have established enhanced partnerships with more than 120 community colleges.

Pell grants are an important component of C4 because they increase access to training and education that lead to high-growth and good paying jobs that sustain families and build vibrant communities. Therefore the importance of Pell grants has increased dramatically for Goodwill.

As members of the Committee know, the Administration's FY 2015 budget proposes to increase the maximum Pell Grant to $5,830. In addition, the budget proposes to include up to $8 billion for the U.S. Departments of Labor and Education to create a Community College Initiative "to support state and community college partnerships with businesses to build the skills of American workers." Goodwill is intrigued by the proposal and believes that such partnerships should leverage the expertise and resources of community-based organizations that provide the supports students need to develop the skills and earn the credentials that employers seek.

Goodwill urges Congress to protect Pell Grants from efforts to further reduce eligibility for many low-income students, and approve the President's proposal to increase the maximum Pell Grant to $5,830.

Senior Community Service Employment Program (SCSEP)

Although the economy is now on a slow but steady path to recovery, today millions of people – including more than 2 million who are 55 and older are still unemployed. Workers who are 55 and older can often have multiple barriers to employment and are among the last rehired as the economy continues to improve. The President's FY 2015 budget again proposes to move SCSEP from DOL to the Department of Health and Human Services' Administration on Aging. Goodwill has serious concerns about the move to HHS and encourages Congress to debate the proposal in depth when it considers reauthorization of the Older Americans Act.

SCESP helps provide low-income older workers with community services employment and private sector job placements. In 2013, Goodwill's SCSEP participants contributed over one million community service hours. Private sector placements averaged a starting wage of over $10 per hour. Individuals placed in unsubsidized employment worked an average of nearly 30 hours per week. In addition, nearly 30 percent of those placed were into positions that offered benefits including health, vacation, and retirement.

Goodwill urges the Subcommittee to increase SCSEP funding by 12 percent to $500,000,000. This increase would help absorb increased costs and account for an increasing number of people who are over age 55. Goodwill urges Congress to thoroughly discuss the proposal to move SCSEP from DOL to HHS when it considers reauthorization of the Older Americans Act.

Youth Mentoring

The Youth Mentoring program, administered by the Department of Justice Office of Juvenile Justice and Delinquency Prevention (OJJDP), supports mentoring for youth at risk of educational failure, dropping out of school, or involvement in delinquent activities, including gangs. FY 2014 funding for this program was $88.5 million and the Administration's FY 2015 budget proposes slashing the program by 34 percent to $58 million. Goodwill is concerned about the impact this cut would have on youth who are at risk. While the constraints of the budget must be recognized, Goodwill believes that mentoring for at-risk youth is proven and strategy that deserves Congress's full support.

Vocational Rehabilitation

Goodwill agencies partner with state VR agencies to provide comprehensive employment and job training services to people with severe disabilities. This longstanding partnership allows Goodwill and State VR agencies to leverage their scarce resources to reach the greatest number of people with disabilities seeking employment. Despite this positive relationship, people are still required to wait for services. For this reason, Goodwill opposes the Administration's proposal to eliminate the Supported Employment State Grants and the Migrant and Seasonal Farmworkers program. These two programs are evidence based with proven outcomes. While the Administration's budget for VR State Grants is increased by $33 million, this increase is offset by the cuts to the Supported Employment State Grants and the Migrant and Seasonal Farmworkers program. As a result there is no net increase in funding for the Vocational Rehabilitation program. This is proposed at a time when the labor market participation rate for people with disabilities is 30 percent – less than half that of people without disabilities.

Goodwill thanks you for considering these requests, and looks forward to working with you to help government meet the serious challenges our nation faces.

THE AMERICAN SOCIETY OF NEPHROLOGY

WRITTEN TESTIMONY IN SUPPORT OF INCREASED FUNDING FOR THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK)

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE OF THE U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

MARCH 28, 2014

The American Society of Nephrology (ASN) is the world's largest kidney health professional organization in the world, representing 15,000 physicians, other healthcare providers, and scientists, and committed to advancing research, prevention, and treatment options for the more than 20 million adults, children, and adolescents with kidney disease in the United States today. The society requests at least $2.066 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH). The society also requests an additional $150 million/year over 10 years for kidney research above current funding for NIDDK.

ASN believes these are crucial and necessary investments for preventing illness and maintaining fiscal responsibility. Investing in research to slow the progression of kidney

disease and identify new therapies will save Medicare spending for the End-Stage Renal Disease (ESRD) Program in the long run.

In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare ESRD Program—the only health entitlement program that provides coverage regardless of age or disability. Today, ESRD patients account for less than 1% of the Medicare population but 7% of the Medicare budget. Meanwhile, at approximately $650 million per year, total federal funding for kidney research is equivalent to less than 1% of the nearly $77 billion Medicare spends annually for the care of patients with kidney disease.

Given that the Medicare ESRD Program is unique in that it covers treatment for all patients with kidney failure regardless of age or disability, preventing kidney disease and improving therapy—starting with innovative research at NIDDK—would yield significant savings to the Centers for Medicare and Medicaid Services.

The vast majority of federal research leading to advances in the care and treatment of patients with kidney disease is funded by NIDDK. Examples of critical discoveries arising from NIDDK-funded research are numerous.

For instance, investigative studies supported by NIDDK led to a groundbreaking discovery that helps explain racial and ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and treatment. The finding that African

Americans with two variants of the APOL1 gene are likely to progress to kidney failure faster than other ethnicities paves the way for future research to unlock better preventive therapies and gene-based cures.

Recent findings from NIDDK's Chronic Renal Insufficiency Cohort (CRIC) Study led to the discovery that the progression of kidney disease is associated with less efficient pumping of blood by the heart. Further research exploring the mechanisms for this development could lead to new interventions that could slow down the progression of kidney disease.

Scientists supported by NIDDK have pursued cutting-edge basic, clinical, and translational research. While ASN fully understands the difficult economic environment, the society firmly believes that funding NIDDK is a sound investment to create jobs, support the next generation of investigators, and ultimately provide quality care that is less expensive in order to improve the public health of Americans.

Medical research is a major force in the economic health of communities nationwide: every dollar invested in medical research generates $2.60 in economic activity. America must continue to capitalize on previous investments to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and maintain leadership in the global innovation economy—particularly as other countries increase their investments in scientific research. Most important, a failure to maintain and strengthen NIDDK's ability to support the groundbreaking work of researchers

across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

ASN urges Congress to uphold its longstanding legacy of bipartisan support for biomedical research. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact ASN Manager of Policy and Government Affairs Rachel Meyer at (202) 640-4659 or rmeyer@asn-online.org.

ABOUT ASN

The American Society of Nephrology (ASN) is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's 15,000 physicians, scientists, and other healthcare professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients. For more information, visit ASN's website at www.asn-online.org.

UNITED TRIBES TECHNICAL COLLEGE
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FY 2015 Department of Education Appropriations:
Carl Perkins Act (Tribally Controlled Postsecondary Career and Technical Institutions); Higher Education Act (Title III); Pell Grants

Submitted to the House Labor-HHS-Education Appropriations Subcommittee
March 28, 2014

For 45 years, United Tribes Technical College (UTTC) has provided postsecondary career and technical education, job training and family services to some of the most impoverished, high risk Indian students from throughout the nation. 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 Carl Perkins Act funds represent a significant portion of our operating budget and provides for our core instructional programs. The request of the UTTC Board for FY 2015 is:

- *$10 million for base funding authorized under Section 117 of the Carl Perkins Act* for the Tribally Controlled Postsecondary Career and Technical Institutions program (20 U.S.C. Section 2327). This is $2.3 million above the FY 2014 level and the FY 2013 post-sequestration level. These funds are awarded competitively and distributed via formula. We are seeking a change to the formula which is not so reliant on Indian Student Count in order to avoid dramatic swings in annual awards.
- *Forward Funding.* We ask that the Section 117 Perkins funds, like the other funds under the Carl Perkins Career and Technical Education Act, be put on a forward funded basis.
- *$30 million as requested by the American Indian Higher Education Consortium for Title III-A (Section 316) of the Higher Education Act*, $5 million above the FY 2014 level.

- *Maintain Pell Grants at the $5,830 maximum award level.*

We are disappointed that the FY 2014 Appropriations Act did not restore the FY 2013 Section 117 sequestration even though funding for the overall Perkins Act was restored. Perhaps Section 117 was overlooked as a source of job training as it is in the Higher Education portion of the budget. We all realize the urgent need to better prepare a workforce to meet industry needs. We are part of that undertaking, but need more resources to come closer to our potential.

The Administration's Blueprint for Perkins reauthorization specifically states support for the Tribally Controlled Postsecondary Career and Technical Education program and it includes some national recommendations that UTTC is already implementing including:

- Training that is industry certified *and* provision of postsecondary certificates and degrees.
- Alignment with labor market needs -- the ramifications of the North Dakota Bakken oil boom are seen throughout the state. We saw the need for more certified welders in relation to the oil boom and so expanded our certified welding program for these good paying, in-demand jobs. Similarly, our online medical transcription program was designed to meet the growing need for certified medical support staff. Other courses reflect new emphasis on energy auditing and GIS Technology.
- Articulation agreements between UTTC and junior and senior high schools.
- A broad range of services for our students to help ensure their success.

Additional Information about UTTC. We have:

- Renewed unrestricted accreditation from the North Central Association of Colleges and Schools for July 2011 through 2021, with authority to offer all of our full programs on-line. We have 26 Associate, 20 Certificate and three Bachelor degree programs.

- Services including a Child Development Center, family literacy program, wellness center, area transportation, K-8 elementary school, tutoring, counseling and housing.
- A semester retention rate of 85% and a graduate placement rate of 77%. Over 45% of our graduates move on to four-year or advanced degree institutions.
- Students from 75-88 tribes; 85% of our undergraduate students receive Pell Grants.
- An unduplicated count of undergraduate degree-seeking students and continuing education students of 1391.
- A critical role in the regional economy. Our presence brings at least $34 million annually to the economy of the Bismarck region. A 2005 study showed a projected return on federal investment of 20-1.
- We have recently opened a distance learning center in Rapid City, SD, where there are some 16,000 American Indians in the area. We are also working toward the establishment of an American Indian Specialized Health Care Training Clinic.

Section 117 Perkins Base Funding. Funds 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 are in the bottom quartile of salary for comparable positions elsewhere; and 4) fund program and curriculum improvements.

Perkins funds are central to the viability of our core postsecondary education 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 targeted supplemental funds. Our Perkins funding provides a base level of support while allowing the college to compete for desperately needed discretionary funds.

Forward Funding. We ask that the Appropriations Committees provide one-time funding for Section 117 Perkins to put it on a forward funded basis. We do not know why it is not already forward funded, given that the rest of the Perkins is forward funded. A number of years ago Section 117 was moved to the Higher Education portion of the budget even though it is authorized through the Perkins Act. Perhaps that has something to do with it, although we point out that many education programs are forward funded. Forward funding provides for vital education programs before the start of each school year, which is critically important when appropriations are delayed and the government is funded via Continuing Resolutions.

Title III-A (Section 316) Strengthening Institutions. Among the Title III-A statutorily allowable uses is facility construction and maintenance. We are constantly in need of additional student housing, including family housing. With the completion of a new Science, Math and Technology 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.

While we have 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 what was Fort Abraham Lincoln, as well as housing that was donated by the federal government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings are actually cheaper than rehabilitating the old buildings that now house students.

Pell Grants. We support maintaining the Pell Grant maximum to at least a level of $5,830. This resource makes all the difference in whether most of our students can attend college.

Government Accountability Office (GAO) Report. As you know, in March 2011 the GAO issued two reports regarding federal programs which may have similar or overlapping services or objectives (GAO-11-318SP of March 1 and GAO-11-474R of March 18). Funding from the Bureau

of Indian Education (BIE) and the Perkins Act for Tribally Controlled Postsecondary Career and Technical Institutions were among the programs listed in the supplemental report of March 18, 2011. *The GAO did not recommend defunding these or other programs; in some cases consolidation or better coordination of programs was recommended to save administrative costs.* We are not in disagreement about possible consolidation or coordination of the administration of these funding sources so long as funds are not reduced.

Perkins funds supplement, but do not duplicate, our BIE funds. *It takes both sources of funding to frugally maintain the institution.* Even these combined sources do not provide the resources necessary to operate and maintain the college and we actively seeks alternative funding to assist with curricula, deferred maintenance, and scholarship assistance. The need for postsecondary career and technical education in Indian Country is so great and the funding so small, that there is little chance for duplicative funding. There are only two institutions targeting American Indian/Alaska Native career and technical education at the postsecondary level—UTTC and Navajo Technical University. Combined, these institutions received less than $15 million in FY 2014 federal operational funds ($7.7 million from Perkins; $7 million from BIE), a very modest amount for two campus-based institutions which offer a wide array of training.

* * *

UTTC offers services catered to the needs of our students, many of whom are first generation college attendees and many of whom come to us needing remedial education and services. Although BIE and Section 117 funds do not pay for remedial education, we make this investment through other sources to ensure our students succeed at the postsecondary level.

Thank you for your consideration of our requests.

Testimony on Opioid Overdose Prevention

Daniel Raymond, Policy Director, Harm Reduction Coalition

Presented on March 25, 2014 to the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

I would like to thank Chairman Kingston, Ranking Member DeLauro, and the Members of the Subcommittee for the opportunity to speak today. I am here to provide testimony on reducing opioid overdose mortality, and to request $5 million in funding for CDC and $5 million in funding for SAMHSA to expand critical, life-saving interventions.

The opioid overdose epidemic has reached crisis proportions in recent years. The Centers for Disease Control and Prevention reports that in 2010, opioids – including both prescription painkillers and heroin – were responsible for nearly 20,000 overdose deaths. While prescription painkillers continue to account for the majority of opioid overdoses, deaths from heroin overdose increased by 45% between 2006 and 2010, fueling concerns in several parts of the country that progress in reducing prescription painkiller misuse is being offset by a dramatic rise in heroin use and its attendant social and health consequences, including addiction, hepatitis C, and overdose. For example, in Kentucky, a state on the forefront of comprehensive approaches to the prescription drug overdose epidemic, the Kentucky Injury Prevention and Research Center recently reported that while overall drug overdose deaths have leveled off from 2011 to 2012 after a decade of dramatic increases, promising declines in the number of

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prescription painkiller deaths have been accompanied by a 207% increase in heroin-related overdose deaths from 2011 to 2012.

For these reasons, Harm Reduction Coalition believes that as efforts continue to mount a comprehensive response to prescription painkiller overdoses, it is necessary to incorporate the intertwined rise in heroin misuse and adopt a broader strategic framework to address all opioids. An opioid epidemic framework would maintain and intensify the array of activities such as those aimed at opioid prescribing practices and monitoring programs, safe disposal, patient and public education, regulatory and enforcement actions, and expansion of effective addiction treatment and recovery services. At the same time, the broader opioid epidemic framework recognizes the vital need for additional public health interventions and opportunities, including the role of expanded access to naloxone, alongside heightened attention to the risks of hepatitis C and other blood-borne viruses transmissible through injection drug use.

Naloxone is a generic medication which acts as an opioid antagonist, blocking the effects of opioids such as painkillers or heroin and capable of reviving individuals from opioid overdoses. A substantial body of research and practice has demonstrated that naloxone is safe and effective in the hands of laypersons; in the words of Dr. Nora Volkow, Director of the National Institute on Drug Abuse, "several experimental overdose education and naloxone distribution (OEND) programs have issued naloxone directly to opioid users and their friends or loved ones, or other potential bystanders, along with brief training in how to use these emergency kits. Such programs have been shown to be an effective, as well as cost-effective, way of saving lives."

Dr. Volkow cites data published by CDC showing that through 2010, overdose education and naloxone distribution programs reported preventing over 10,000 opioid overdose deaths across the country. As of this month, eighteen states have passed legislation to facilitate broader access and utilization of naloxone, ranging from Kentucky to Connecticut, Ohio to California; Georgia passed naloxone legislation on March 18th which now awaits the governor's signature. These overdose education and naloxone distribution programs vary in setting and scope. In North Carolina, Project Lazarus trains physicians to co-prescribe naloxone to pain patients receiving opioids. In Massachusetts, support groups for parents with children struggling with opioid dependence are trained and provided with naloxone. In Rhode Island, naloxone is provided through pharmacies. In Kentucky, some of the strongest advocates for naloxone have been the addiction recovery community. In New York, my organization has provided naloxone training to dozens of drug treatment programs, syringe exchange programs, shelters, and law enforcement agencies. In other parts of the country, overdose education and naloxone distribution programs are launching in emergency departments, jails, and Veterans Administration Medical Centers.

These programs are gaining increased federal attention; in the last month, the Attorney General echoed the Office of National Drug Control Policy in calling upon first responders and law enforcement officers to be trained and equipped with naloxone. The Agency for Healthcare Research and Quality highlighted the Massachusetts overdose education and naloxone distribution program and featured accompanying quality tools, including an overdose and naloxone program manual from the Harm Reduction Coalition. Last year, the Substance Abuse and Mental Health Services Administration (SAMHSA) released an opioid overdose toolkit

featuring naloxone. NIDA and FDA have worked to support and facilitate the development of new, consumer-friendly formulations of naloxone. The Ohio Department of Health's Violence and Injury Prevention Program has used a portion of its CDC injury prevention funding to expand Project DAWN, an overdose education and naloxone distribution program, to additional counties.

The President's FY 2015 budget requests $26 million to prevent prescription drug overdose, of which $16 million would expand CDC's Core Violence and Injury Prevention Program grants to states, with an expected $10 million directed to prescription drug overdose activities, and $10 million to SAMHSA would fund state planning grants to develop prevention strategies for prescription drug abuse. The Harm Reduction Coalition supports these proposals, and believes that these resources would be valuable in establishing a foundation to reverse the prescription drug overdose epidemic. We also believe that additional emergency funding is necessary to stem the tide of opioid overdose from both prescription opioids and, increasingly, heroin. Within the context of a comprehensive approach to the opioid epidemic, including expanding access to addiction treatment and recovery, the Harm Reduction Coalition views the rapid expansion and scale up of overdose education and naloxone distribution programs as an urgent and underfunded priority to save lives.

To that end, we request that $5 million be provided to CDC Injury Prevention and Control to support opioid overdose fatality prevention efforts within state and local health departments and community-based organizations to strengthen their ability to deliver overdose recognition and intervention training and education, and expand access to rescue medications and other evidence-based strategies.

We also request that $5 million be provided to SAMHSA's Center for Substance Abuse Treatment to support community-based opioid overdose fatality prevention efforts, with a focus on those initiatives that provide overdose recognition and intervention training and education, access to rescue medications, and facilitate linkage to treatment and recovery services.

Across the country, emerging overdose education and naloxone distribution programs rely on limited funding to meet a growing need. The availability of targeted federal funds through both the public health and addiction treatment and recovery communities would hasten the expansion of these programs to meet growing need and demand.

In the battle against opioid overdose, there is much to be done, and no time to lose. We need a twofold approach of long-range efforts to address the underlying causes and factors which led to the initial rise in prescription opioid misuse, coupled with immediate actions to avert additional deaths and tragedies in the short-term. As a person who has lost friends and loved ones to opioid overdose, and listened to the stories of grieving parents who only wish someone had told them about naloxone before it was too late for their children, I respectfully ask for your consideration of our requests.

If you have any questions, or would like more information or data on naloxone, please feel free to contact me: Daniel Raymond, raymond@harmreduction.org, (212) 213-6376 x29. Thank you for your attention and consideration.

Testimony from the American Academy of Physician Assistants for Fiscal Year 2015 Appropriations Concerning the Health Resources and Services Administration's Title VII Health Professions Program

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

Submitted by: Sandy Harding, MSW, Senior Director, Federal Advocacy

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On behalf of the more than 95,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants (AAPA) is pleased to submit comments on Fiscal Year 2015 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service (PHS) Act. **AAPA respectfully requests the House Appropriations Committee to approve funding at existing levels for the Title VII health professions education program - $280,000,000, with an allocation of 15% of the Primary Care Training and Enhancement program line for PA educational programs.**

Federal support for Title VII is authorized through section 747 of the PHS Act. It is the only continuing federal funding available to PA educational programs. Unfortunately, in recent years, PA educational programs have received reduced support from Title VII funding, which is designed to educate PAs in primary care and to prepare PAs for practice in urban or rural medically underserved areas.

This funding is essential to the development and training of the nation's health workforce, and is critical to providing continued access to health services in underserved and minority communities. It also encourages PAs to return to these environments with the greatest need after they have completed their educational preparation, being one of the best recruitment tools to date. According to the Health

Resources and Services Administration (HRSA), 37 percent of Pas practice in medically underserved counties, including medically underserved areas and medically underserved populations.

Additionally, Title VII funding has helped PA Programs expand clinical rotations in rural and underserved areas that have been in critically short supply and has enhanced primary care curriculum to better address the needs of disadvantaged populations.

While the purview of the Title VII programs grant funding has expanded to include assisting returning combat veterans, funding for PA educational programs has been significantly reduced. Additional reductions to this budget will disadvantage new PA programs that need these funds to help with student recruitment, faculty development, and establishing clinical rotation cites.

Diverse clinical rotation sites and recruitment programs are critical to PA education and are paramount to the Title VII primary care medicine program. A review of PA graduates from 1990 – 2009 demonstrated 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. 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 augment funding to these important programs in FY 2015.

Overview of PA Education

The existing 181 accredited physician assistant educational programs are all 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 PA curriculum includes 400 hours of

basic sciences and nearly 1,600 hours of clinical medicine. On average, students devote more than 2,000 hours, or 50 to 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.

After graduating from an accredited PA program, PAs must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants and become licensed by the state to provide medical care.. To maintain certification, PAs must log 100 continuing medical education hours every two years, and they must take a recertification exam every ten years.

PA Practice

PAs are licensed health professionals who practice medicine as members of a healthcare team. 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. PAs perform physical examinations, diagnose and treat illnesses, order and interpret lab tests, assist in surgery, provide patient education and counseling, and make rounds in nursing homes and hospitals. PAs are nationally certified and state licensed to practice medicine and prescribe medication in all fifty states, the District of Columbia, the Commonwealth of the Northern Mariana Islands, Guam, and the U.S. Virgin Islands.

PAs in Primary Care

An estimated 30,000 PAs (32 percent of the profession) work in primary care across the nation – 38.2 percent work in private practice (multi-and single specialty and solo practices); 23.3 percent in Family Medicine, 3.0 percent practice in community health centers, 3.3 percent practice in certified rural health clinics, and 2.7 percent work in a federally qualified health center.

PAs are also one of three primary care providers who provide medical care through the National Health Service Corps (NHSC). The NHSC is an important federal program with nearly 10,000 healthcare

providers, like PAs, who benefit from the program's loan-forgiveness and scholarship awards to those providers and students who commit two years to provide medical, dental, and mental healthcare in medically underserved areas.

Additionally, PAs provide medical care in community health centers (CHCs), some as CHC medical directors. CHCs provide cost-effective healthcare throughout the country and serve as medical homes for millions in medically underserved areas. CHCs offer a wide variety of healthcare services through team-based care, providing high quality healthcare to CHC patients and significantly reducing medical expenses.

Critical Role of the Title VII PHS Act Programs

According to the Health Resources and Services Administration (HRSA), an additional 31,000 healthcare providers are needed to alleviate existing professional shortages. This existing shortage, combined with faculty shortages across PA education, the need to build greater diversity among healthcare providers, and an increasingly aging healthcare workforce, creates challenges in growing the primary healthcare 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 not 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.** Research shows racial and ethnic health disparities

cost the economy more than $230 billion in lost productivity and up to $1.24 trillion in indirect costs over three years; and 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 which would help alleviate the current health disparity crisis in America.

Support for educating PAs to practice in underserved communities is particularly important given the market demand for PAs. Title VII funding is a critical link in addressing the natural geographic mal-distribution 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.

Supplementary Recommendations on FY 2015 Funding

AAPA urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and programs when determining funding for FY 2015. 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 HRSA 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, the CDC is heavily dependent upon an adequate supply of healthcare providers to be sure that disease outbreaks are reported, tracked, and contained.

Thank you for the opportunity to present the AAPA's views on FY 2015 appropriations concerning HRSA's Title VII Health Professions Program.

Angela L. Sharpe, COSSA, (202) 842-3525 (alsharpe@cossa.org)

Statement of the Consortium of Social Science Associations on FY 2015 Funding for the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC) and the Agency for Healthcare Research and Quality (AHRQ) 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 Jack Kingston, Chair, March 28, 2014

Mr. Chairman and Members of the Subcommittee, the Consortium of Social Science Associations (COSSA) appreciates and welcomes the opportunity to comment on the Fiscal Year (FY) 2015 appropriations for the **National Institutes of Health** (NIH), **Centers for Disease Control and Prevention** (CDC) and the **Agency for Healthcare Research and Quality** (AHRQ). ***COSSA joins the Ad Hoc Group for Medical Research in recommending that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in our nation's investment in medical research. As a member of the CDC Coalition, COSSA requests $7.8 billion in funding for the CDC in FY 2015. We join the Friends of AHRQ in requesting a funding level of $375 million for AHRQ in FY 2015.***

COSSA is an advocacy group for the social and behavioral sciences supported by more than 100 professional associations, scientific societies, universities and research centers. It serves as a bridge between the academic research and Washington policy-making community. Our organizations are appreciative of the Subcommittee's and the Congress' continued support of NIH, CDC, and AHRQ. Strong, sustained funding for these agencies is essential to the national priorities of better health and economic revitalization.

NIH Behavioral and Social Sciences Research: As this Committee knows, the NIH mission is to support **scientifically rigorous, peer/merit-reviewed, investigator-initiated research,** including basic and applied behavioral and social science research in fulfilling its mission: "Science in pursuit of **fundamental knowledge** about the **nature and behavior** of living

systems and the **application** of that knowledge to enhance health, lengthen life and reduce illness and disability."

The fundamental understanding of how disease works, including the impact of social environment on these disease processes, underpins our ability to conquer devastating illnesses. Perhaps the grandest challenge we face is to understand the brain, behavior, and society— from responding to short-term pleasures to self-destructive behavior, such as addiction, to lifestyle factors that determine the quality of life, infant mortality rate and longevity. And while Americans have achieved very high levels of health over the past century and are healthier than people in many other nations, according to the 2013 National Academies' (NAS) report, *U.S. Health in International Perspective: Shorter Lives, Poorer Health*, "a growing body of research suggests that the health of the U.S. population is not keeping pace with the health of people in other economically advanced, high-income countries."

Nearly 125 million Americans are living with one or more chronic conditions, including heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. At the same time, health care spending in the United States is being driven up by the aging of the U.S. population and the rapid rise in chronic diseases, many of which are caused or exacerbated by behavioral factors—including, obesity, caused by sedentary behavior and poor diet, and addictions resulting from health problems caused by tobacco and other drug use. As the NAS report notes, "the United States is losing ground in the control of diseases, injuries, and other sources of morbidity."

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 role behavior plays in our health. At a time when

genetic control over disease 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 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. This includes NIH's support of economic research, specifically, research on the linkages between socioeconomic status and health outcomes in the elderly and achievement and health outcomes in children. **This research has been an integral part of the interdisciplinary science NIH has historically supported**. Accordingly, the agency's investment has yielded key data, methodologies and substantive insights on some of the most important and pressing issues facing the U.S. For example, NIH-funded surveys such as the Health and Retirement Survey, the Panel Study of Income Dynamics (PSID), parts of the National Longitudinal Survey of Labor Market Experiences, and surveys on international aging and retirement provide data necessary to monitor and detect changes in important socioeconomic trends in health. This in turn allows NIH to support research that will provide the greatest return on its investment when it comes to the health of our citizens.

CDC Behavioral and Social Science Research: As the country's leading health protection and surveillance agency, the Centers for Disease Control and Prevention (CDC) works with state, local, and international partners to protect Americans from infectious diseases;

prevent the leading causes of disease, disability, and death; protect Americans from natural and bioterrorism threats; monitor health and ensure laboratory excellence; keep Americans safe from environmental and work-related hazard; and ensure global disease protection.

Social and behavioral science research plays a crucial role in helping the CDC carry out its mission. Scientists in fields ranging from psychology, sociology, anthropology, and geography to health communications, social work, and demography work in every CDC Center to design, analyze, and evaluate behavioral surveillance systems, public health interventions, and health promotion and communication programs using a variety of both quantitative and qualitative methods. These scientists play a key role in the CDC's **surveillance and monitoring** efforts, which collect and analyze data to better target public health prevention efforts. Another vital contribution of the social and behavioral sciences to CDC activities is in identifying and **understanding health disparities**. Finally, the social and behavioral sciences play an important role in the evaluation of CDC programs, helping policymakers make **informed, evidence-based decisions** on how to prioritize in a resource-scarce environment.

The CDC is also the home of the nation's principal health statistics agency, the **National Center for Health Statistics** (NCHS). 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. It provides **critical data on all aspects of our health care system** through data cooperatives and surveys that serve as the gold standard for data collection around the world. Data from NCHS surveys like the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES) and the National Vital Statistics System (NVSS) are used by agencies across the federal government, state and local

governments, public health officials, federal policymakers, and demographers, epidemiologists, health services researchers, and other scientists.

AHRQ Health Services Research: AHRQ's sole purpose is to improve health care in America. Just as biomedical research helps us find cures for disease, the health services research AHRQ supports helps find ways to cure our health care system—improving its quality, safety, and efficiency for the benefit of patients. AHRQ's research identifies what works and what doesn't in health care to improve patient care and provide policymakers and other health care leaders with the information needed to make critical health care decisions.

AHRQ helps providers help patients. AHRQ's research generates valuable evidence to help providers help patients make the right health care decisions for themselves and their loved ones. The science funded by AHRQ ensures patients receive high quality, appropriate care every time they walk through the hospital, clinic, and medical office doors. AHRQ's research provides the basis for protocols that prevent medical errors and reduce healthcare-associated infections (HAIs), and improve patient experiences and outcomes. AHRQ helps health care providers—from private practice physicians to large hospital systems—understand how to deliver the best care most efficiently. The breadth of evidence available from AHRQ empowers health care providers to understand not just how they compare to their peers, but also how to improve their performance to be more competitive.

COSSA expects this testimony to be only the beginning of an ongoing conversation between the Subcommittee and stakeholders on the FY 2015 funding needs of these agencies.

We would be pleased to provide any additional information.

Consortium of Social Science Associations

Written Testimony for the Record by the

NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS

Submitted by *Timothy R. Warfield, Executive Director*

Related to Appropriations by the

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

Concerning the **COMMUNITY SERVICES BLOCK GRANT**

March 28, 2014

Mr. Chairman and Members of the committee, thank you for the opportunity to submit this testimony on behalf of the National Association for State Community Services Programs (NASCSP), a membership association for the administrators of the federally-funded Community Services Block Grant which serves millions of American families in communities across the country. As the Executive Director of NASCSP, I submit this testimony on behalf of the states in their work to improve the lives of low-income families and strengthen local economies. We are requesting that the Committee approve $710 million in FY 2015 to adequately fund the CSBG network. This level of funding is the same as the FY 2014 enacted funding for CSBG. We strongly believe that CSBG is a wise strategic investment not only in America's ongoing economic recovery, but in our nation's long-term economic stability as well. Maintaining funding is necessary not only to continue CSBG's well-documented role in strengthening our economy, but also for the ongoing reforms to the block grant which adapt it to new realities and strengthen it for the next generation. We strongly oppose the reduction in funding for CSBG as proposed by the Administration, and I welcome this opportunity to explain exactly why.

First, however, I'd like to thank Congress for its past support of CSBG. The services provided by this network are crucial to the millions of Americans facing poverty and economic insecurity at a time when the impact of the slow economy is affecting every Congressional District in America. Right now, more than 46 million Americans are living below the federal poverty level (defined as $23,050 a year for a family of four). CSBG directly addresses the need to help hard-working Americans who are struggling in the present economy and to prevent people from slipping further into poverty. The strength and productivity of our nation depends on the economic well-being of all of its citizens, and CSBG is a proven strategy to support millions of low-income Americans on the path to economic security. The CSBG network uses grassroots, innovative strategies to alleviate poverty and provides a significant return on taxpayers' investment. In fiscal year 2012, the CSBG network leveraged $22.75 for every federal dollar invested in CSBG.

By acting as a conduit between the federal administration and local community action agencies (CAA's), States build public-private partnerships, support innovation, and advance best practices to ensure the most effective use of taxpayers' money. Local agencies utilize CSBG funds to leverage additional funds to eliminate poverty through a variety of programs and services. While CAAs across the nation address similar issues, local needs determine unique approaches to addressing them.

Poverty is a national problem, but can only be effectively addressed at the grassroots level. The CSBG network strives to find local solutions to these community issues by conducting

community needs assessments to keep in touch with the needs, challenges, and resources in their community. The community needs assessments enable CAAs to provide the most effective and efficient strategies and services. These efforts fall into nine service categories outlined in the CSBG Act; employment, education, income management, housing, emergency services, nutrition, linkages, self-sufficiency, and health.

National data compiled by NASCSP shows that CSBG serves a broad segment of low-income individuals and families. Data from fiscal year 2012 shows:

- There are 1,045 CAAs across the country, serving 99% of US counties;
- CSBG serves 1 out of every 5 people in America below the poverty line;
- The majority of clients are female (58%), white (59%), renters (60%) and between the ages of 24 – 44 years old (24%)—the second largest group was children ages 0-5 years old (14%);
- The majority of clients are receiving incomes from employment-related sources (50%);
- Many of the families served (33%) were in "severe poverty," with incomes below 50% of the Federal Poverty Guideline.

The successes of the CSBG network are well documented:

- CSBG served 16 million Americans including 76.9 million families in FY 2012.
- Over the past 5 years, the CSBG network helped over 630,000 people obtain employment.

- Over the past 5 years, the CSBG network addressed 21.2 million barriers to employment through helping people to either acquire jobs, obtain employment supports, or to receive job training.
- Over the past 5 years, the CSBG network expanded 19.8 million community opportunities or resources to stimulate community and economic development.
- Over the past 5 years, the CSBG network facilitated 18.5 million opportunities for infants, children, youth, parents and other adults through developmental or enrichment programs.

States provide administrative oversight to ensure that eligible entities are meeting State and Federal requirements as well as their locally driven Community Action Plans. This includes monitoring eligible entities, providing training and technical assistance, investing in innovation, and maintaining effective performance measurement and management systems. Adequate funding is needed to maintain a high level of accountability and performance in the following areas:

Support High Achievement and Innovation

Adequate funding, sufficient to meet national standards and incentives must be provided to States, local agencies, and national partners for high achievement and innovation. CSBG appropriations should include sufficient resources for local agencies, States, and national partners to engage in the work necessary to achieve the goals of the CSBG Act and the Promise of Community Action, which includes addressing the needs of vulnerable people and building strong communities. It should create the opportunity to provide a consistent resource to the

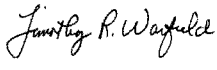
people, families and communities that benefit from the activities conducted under the Act. It should also provide funds to extend the work to create and test innovative approaches as well as include and engage an ever wider circle of partners.

Support Coordination of Services

NASCSP believes that a $710 million funding level for CSBG is essential for continued innovation and stronger coordination. It will also maintain the stature of the CSBG in both State and Federal administrations. Further, adequate funds in the CSBG will create additional opportunities and development for low-income programs and will allow for further coordination with agencies outside our Network that share a similar mission.

Mr. Chairman, I respectfully request the Committee to fund CSBG at the level of $710 million in FY 2015 to support America's ongoing economic recovery and future economic stability. Maintaining CSBG funding is an investment in both strengthening our economy and in adapting our efforts to new realities for future generations of hard-working Americans. Thank you.

Sincerely,



Timothy R. Warfield
Executive Director

TESTIMONY OF

Harry P. Selker, MD, MSPH
Dean, Tufts Clinical and Translational Science Institute
Executive Director, Institute for Clinical Research and Health Policy Studies

ON BEHALF OF

The Coalition for Clinical and Translational Science (CCTS), which includes
Association for Clinical and Translational Science, 2025 M St NW, # 800, Washington, DC 20036;
The Clinical Research Forum, 6701 Democracy Blvd, # 300, Bethesda, MD 20817;
and other stakeholders

REGARDING

Fiscal Year 2015 (FY15) appropriations for clinical and translational research and research training and career development programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO

The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON

The 28th Day of March, 2014

THE COALITION'S FY15 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**

- **$32 billion in program level funding for the National Institutes of Health (NIH) to facilitate increased support for the full spectrum of medical research and also for research training and career development activities.**
    - **At least $500 million for the Clinical and Translational Science Awards (CTSA) Program at NIH as part of a continued effort to provide the full funding level of $750 million.**
    - **Implementation of the Institute of Medicines' CTSA Recommendations.**
    - **Proportional funding increases for additional clinical and translational research activities at NIH, including the Institutional Development Awards Program and the Research Centers at Minority Institutions Program.**

- **Provide a meaningful funding increase for the Agency for Healthcare Research and Quality (AHRQ) to facilitate increased support for research training and career development activities, and clinical research activities.**

Chairman Kingston and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the clinical and translational research community as you work to craft the FY15 L-HHS Appropriations Bill. Before I begin, the community would like to thank you for your past support of the full spectrum of medical research.

ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

CCTS is the unified voice of the clinical and translational science research community. CCTS is a nationwide, grassroots network of dedicated individuals who work together to educate Congress and the Administration about the value and importance of federal clinical and translational research and research training and career development activities. CCTS's goals are to ensure that the full spectrum of medical research is adequately funded, the next generation of researchers is well-prepared, and the regulatory and public policy environment facilitates ongoing expansion and advancement of the field of clinical and translational science.

Association for Clinical and Translational Science (ACTS)

ACTS supports investigations that continually improve team science, integrating multiple disciplines across the full translational science spectrum: from population based and policy research, through patient oriented and human subject clinical research, to basic discovery. Our goal is to improve the efficiency with which health needs inform research and new therapies reach the public.

ACTS is the academic home for the disciplines of research education, training, and career development for the full spectrum of translational scientists. Through meetings, publications, and collaborative efforts, ACTS will provide a forum for members to develop, implement, and evaluate the impact of research education programs.

ACTS provides a strong voice to advocate for translational science, clinical research, patient oriented research, and research education support. We will engage at the local, state, and federal levels and coordinate efforts with other professional organizations.

ACTS will promote investigations and dissemination of effective models for mentoring future generations of translational scientists. Through collaborative efforts, ACTS will provide a forum for members to share studies, promote best practices, and optimize professional relationships among trainees and mentors.

The Clinical Research Forum (CRF)

CRF was formed in 1996 to discuss unique and complex challenges to clinical research in academic health centers. Over the past decade, it has convened leaders in clinical research annually and has provided a forum for discussing common issues and interests in the full spectrum of research. Through its activities, the Forum has enabled sharing of best clinical

practices and increasingly has played a national advocacy role in support of the boarder interests and needs of clinical research.

Governed by a Board of Directors constituted of clinical researchers from thirteen member institutions, CRF has grown to sixty members from academia, industry, and volunteer health organizations. CRF engages leaders in the clinical research enterprise including leaders from government, foundations, other not-for-profit organizations, and industry in addressing the challenges and opportunities facing the clinical research enterprise.

Parallel with our widening focus upon the broad needs of the entire national clinical research enterprise, CRF is committed to working in those areas where it is uniquely positioned to have a significant impact. Collaboration with other organizations with similar goals and synergizing with their efforts strengthens all approaches to the issues facing clinical research.

SEQUESTRATION

Thank you for providing sequestration relief in FY 2014 and FY 2015.

Federal medical research programs form the cornerstone of our nation's biotech sector. In addition to undermining active and emerging research projects, across the board funding cuts create widespread disruption. Due to a number of factors, this disruption compounds significant challenges facing the clinical and translational research training and career development pipeline.

Recent years of near-level funding have curtailed NIH's ability to issue funding opportunities. As a result, the pay line at NIH has decreased substantially while the average age of an investigator receiving their first award has increased significantly. This dynamic creates a strong disincentive for young people to pursue a career in this field. Prior to sequestration, NIH would often discuss the decline in young investigators entering the research training and career development pipeline.

Beyond public health, our country needs to ensure that we are adequately preparing the next generation of medical investigators for reasons related to both the economy and national security. Last year, China announced a $300 billion five-year investment in medical research; this amount is double the current NIH budget over the same period of time. With strong competition from foreign countries, we run the risk of a researcher brain-drain from the U.S. to other nations. Scientific breakthroughs and innovation will continue, but our loss in this area will mean gains for other nations. Foreign economies will benefit from the significant return-on-investment that occurs through robust support of research.

Sequestration has the potential to severely exacerbate an already difficult task of recruiting and training the next generation of scientific investigators. In order to ensure that the U.S. maintains a strong research training and career development pipeline, please eliminate the threat of sequestration and further support key activities.

NATIONAL INSTITUTES OF HEALTH

This nation has a proud history as a global leader in medical research and biotechnology. This leadership has provided our country with cutting-edge patient care, high-quality jobs, and meaningful economic growth. The Milliken Institute recently calculated that every dollar invested in NIH returns about a $1.70 in economic output in the short term and as much as $3.20 long-term. Crucially, through a robust external research program, NIH resources flow out to the states where the benefit of the funding infusion is felt on the local level.

NIH's impact on public health has been profound. Conditions once considered a death-sentence can now be managed, survival rates for patients with life-threatening diseases have increased dramatically, and additional innovative therapies and diagnostic tools come to market each year. NIH has been successful, but much more can be done. Please provide NIH with at least $32 billion in FY 2015 so ongoing research projects can be adequately supported and new research activities can be initiated.

Clinical and Translational Science Awards (CTSA)

NIH's CTSA Program, which is housed within the National Center for Advancing Translational Sciences (NCATS), is transforming the efficiency and effectiveness of clinical and translational research. Since its establishment with 13 centers, the CTSA program has expanded to 62 medical research institutions located across the country. These centers are linked together and work in concert to improve human health by energizing the research and training environment to innovate and enhance the quality of clinical and translational research.

Last year, the Institute of Medicine (IOM) released a review of the CTSA program. The report entitled, *The CTSA Program at NIH: Opportunities for Advancing Clinical and Translational Research*, spoke favorably of the CTSA effort and made the following recommendations to improve the program:

(1) Strengthen NCATS leadership of the CTSA program, (2) reconfigure and streamline the CTSA Consortium, (3) build on the strengths of individual CTSAs across the spectrum of clinical and translational research, (4) formalize and standardize evaluation processes for individual CTSAs and the CTSA Program, (5) advance innovation in education and training programs, (6) ensure community engagement in all phases of research, (7) strengthen clinical and translational research relevant to child health.

CCTS supports the recommendations of the IOM report and the organization is hopeful these changes will be implemented quickly. Further, when the CTSA program was authorized, Congress indicated that the consortium would be considered fully-funded when it received an annual appropriation of $750 million. For FY 2015, as part of an overall funding increase for NIH, please provide CTSAs with at least $500 million to ensure the program can continue to grow and advance. Additionally, we hope you will continue working over the coming years to

provide CTSAs with $750 million to fully fund the program and establish a robust home for clinical and translational research.

Additional Programs

In recent years, Congress and NIH have made important investments to support the full spectrum of medical research. Key clinical and translational research programs at NIH include Research Centers at Minority Institutions (RCMI), Institutional Development Awards (IDeA), and the new Accelerating Medicine Partnership (AMP). Supporting the full spectrum of medical research encourages outcomes-oriented investigation where breakthroughs in basic science are translated to new diagnostic tools and treatments that improve health and lower healthcare expenses. In recognition of the future of the overall field of medical research, most individual NIH Institutes and Centers now provide some level of support for translational and clinical research activities.

In order to ensure that clinical and translational research programs at NIH have adequate support to facilitate ongoing growth, please provide $32 billion for NIH in FY 2015 with proportional increases for individual Institutes, Centers, and Offices.

FEDERAL RESEARCH TRAINING AND CAREER DEVELOPMENT PROGRAMS

As we discussed previously, the future of our nation's biomedical research enterprise relies heavily on the maintenance and continued recruitment of promising young investigators. The "T" and "K" series awards at NIH and AHRQ provide much-needed support for the career development of young investigators. As clinical and translational medicine takes on increasing importance, there is a great need to grow these programs. 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 and T awards would have a devastating impact on our pool of highly trained clinical researchers. CCTS urges you to support the ongoing commitment to research training through adequate funding for T and K series awards and a meaningful FY 2015 funding increase for AHRQ.

Thank you for the opportunity to present the views and recommendations of the clinical and translational research and research training and career development community.

TESTIMONY OF
Ken Singleton
Executive Director

ON BEHALF OF
The GBS/CIDP Foundation International (GCFI)
104½ Forrest Avenue
Narbeth, PA 19072

REGARDING
Fiscal Year 2015 (FY15) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 28th Day of March, 2014

THE FOUNDATION'S FY15 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**

- **$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY2015 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

- **$32 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Institute of Neurological Disorders and Stroke (NINDS), National Institute of Allergy and Infectious Diseases (NIAID), and National Center for Advancing Translational Sciences (NCATS).

Chairman Kingston and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and related conditions as you work to craft the FY15 L-HHS Appropriations Bill.

ABOUT GBS AND CIDP

Guillain-Barré Syndrome
GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. It's also known as Acute Inflammatory Demyelinating Polyneuropathy and Landry's Ascending Paralysis.

The cause of GBS is unknown. We do know that about 50% of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning. Some theories suggest an autoimmune trigger, in which the patient's defense system of antibodies and white blood cells are called into action against the body, damaging myelin (nerve covering or insulation), leading to numbness and weakness.

GBS in its early stages is unpredictable, so except in very mild cases, most newly diagnosed patients are hospitalized. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood "cleansing" procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months, with over 90% of patients moving into the rehabilitative phase within four weeks. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Some patients require speech therapy if speech muscles have been affected.

Recovery may occur over six months to two years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches. These can be aggravated by 'normal' activity and can be alleviated by pacing activity and rest.

Chronic Inflammatory Demyelinating Polyneuropathy
CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms.

It is the gradual onset as well as the *chronic* nature of CIDP that differentiates it from GBS. Fortunately, CIDP is even more rare than GBS. The incidence of new cases is estimated to be between 1.5 and 3.6 in a million people (compare to GBS: 1-2 in 100,000).

Like GBS, CIDP is caused by damage to the covering of the nerves, called *myelin*. It can start at any age and in both genders. Weakness occurs over two or more months.

Unlike GBS, CIDP is not self-limiting (with an end to the acute phase). Left untreated, 30% of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. Patients respond in various ways. The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may take several courses of treatment before benefits are seen. The chronic nature of CIDP differentiates long-term care from GBS patients. Adjustments inside the home may need to be made to facilitate a return to normal life.

ABOUT THE FOUNDATION

The Foundation's vision is that every person afflicted with GBS, CIDP, or variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

The Foundation's mission is to improve the quality of life for individuals and families across America affected by GBS, CIDP, and their variants by:

- Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.
- Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.
- Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that research into GBS, CIDP, and related disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in FY13 was $6 billion (22.4 percent) less than it was in FY03.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since FY03. In FY 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in FY03.
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The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong

disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CIDP is a progressive condition with serious health impacts. Patients can end up almost completely paralyzed and on a ventilator. The key to limiting serious health impacts is an early and accurate diagnosis. The time it takes for a CIDP patient to begin therapy is linked to the length of therapy and the seriousness of the health impacts. An early diagnosis can mean the difference between a 3 month or 18 month hospital stay, or no hospitalization at all. For the federal healthcare system, there is an economic incentive to ensure early and accurate diagnosis as longer hospitalizations equate to higher costs.

CDC and NCCDPHP have resources that could be brought to bear to improve public awareness and recognition of CIDP and related conditions. In order to initiate new, potentially cost-saving programs, CDC requires meaningful funding increases to support crucial activities.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest research portfolio focused on GBS, CIDP, and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. In fact, NINDS, NIAID, and the Office of Rare Diseases Research (ORDR) housed within NCATS have expressed interest in hosting a State-of-the-Science Conference on autoimmune peripheral neuropathies. This conference would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade. While such a conference would not require additional appropriations, the Foundation urges you to provide NIH with meaningful funding increases to facilitate growth in the GBS, CIDP, and related conditions research portfolio.

Thank you for your time and your consideration of the community's requests.

TESTIMONY OF
Carolyn S. Levering
President and CEO

ON BEHALF OF
The National Marfan Foundation (NMF)
22 Manhasset Ave.
Port Washington, NY 11050

REGARDING
Fiscal Year 2015 (FY15) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 28th Day of March, 2014

THE FOUNDATION'S FY15 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**

- **$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY2015 funding increase for CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD).

- **$32 billion in program level funding for the National Institutes of Health (NIH).**
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); and National Center for Advancing Translational Sciences (NCATS).

Chairman Kingston and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the heritable connective tissue disorders community as you work to craft the FY15 L-HHS Appropriations Bill.

ABOUT MARFAN SYNDROME AND HERITABLE CONNECTIVE TISSUE DISORDERS

Marfan Syndrome
Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue holds all the body's cells, organs and tissue together. It also plays an important role in helping the body grow and develop properly.

Connective tissue is made up of proteins. The protein that plays a role in Marfan syndrome is called fibrillin-1. Marfan syndrome is caused by a defect (or mutation) in the gene that tells the body how to make fibrillin-1. This mutation results in an increase in a protein called transforming growth factor beta, or TGF-β. The increase in TGF-β causes problems in connective tissues throughout the body, which in turn creates the features and medical problems associated with Marfan syndrome and some related disorders.

Because connective tissue is found throughout the body, Marfan syndrome can affect many different parts of the body, as well. Features of the disorder are most often found in the heart, blood vessels, bones, joints, and eyes. Some Marfan features – for example, aortic enlargement (expansion of the main blood vessel that carries blood away from the heart to the rest of the body) – can be life-threatening. The lungs, skin and nervous system may also be affected. Marfan syndrome does not affect intelligence.

Related Conditions
There are disorders related to Marfan syndrome that can cause people to struggle with some of the same or similar physical problems. Some examples are Loeys-Dietz syndrome, Ehlers-Danlos syndrome, and Familial Thoracic Aortic Aneurysm and Dissection.

Disorders related to Marfan syndrome can also cut lives short, particularly when they go unchecked, and they can deeply affect the quality of life of the individuals and families who must cope with them. Just like people with Marfan syndrome, those affected by related disorders need early and accurate diagnosis to ensure they receive proper care and treatment.

Many of these disorders are genetic conditions that, like Marfan syndrome, cause the aorta (the main blood vessel that carries blood from the heart to the rest of the body) to enlarge, a problem that requires medicine and regular monitoring to determine appropriate treatment. Other features that may overlap with Marfan syndrome include those involving the heart, bones, joints and eyes. Related connective tissue disorders include:

- Loeys-Dietz Syndrome
- Ehlers-Danlos Syndrome
- Familial Thoracic Aortic Aneurysm and Dissection
- Mass Phenotype
- Ectopia Lentis Syndrome
- Beals Syndrome

- Bicuspid Aortic Valve
- Stickler Syndrome
- Shprintzen-Goldberg Syndrome

ABOUT THE FOUNDATION

The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders.

- We pursue the most innovative research and make sure that it receives proper funding.
- We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
- We provide relentless support to families, caregivers, and healthcare providers.

We will not rest until we've achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

ONE FAMILY'S STORY

Hector Roman was 36 years old when he died on June 25, 2012, of an aortic dissection caused by Marfan syndrome. He was never diagnosed with Marfan syndrome – despite being treated by several medical specialists for myriad health issues – and he did not know he was a risk of a sudden early death. He was in pain for days and didn't rush to the hospital because he was frustrated with the lack of help he was getting with his health concerns. He had no idea this delay would be deadly. After a few days in pain, he went into shock and a friend call 911. He died three days later during his third surgery.

Now, his partner, Teresita Mompeller, of Phoenix, AZ, is raising their three boys -- Jovan,5, Joel, 3, and Justus, 2 – alone. After Hector died, Teresita learned about Marfan syndrome. Most alarming to her was that affected people have a 50 percent chance of passing it to their offspring. She had her sons checked immediately. Joel and Justus have been diagnosed with Marfan syndrome and already have aortic enlargement. While their condition is the same as their dad; their prognosis is better. The boys can live a normal life span because they have the diagnosis and are being monitored. They can avoid a fatal situation because they *know*.

Teresita, who has a Facebook page called "Do You Know Marfan?" (and a parallel page in Spanish) recently wrote: "Thanks to the work of The Marfan Foundation, I know that my boys have a greater chance of living a long life. I know first-hand what it is to be a mother with many questions and concerns about a rare disorder that nobody seemed to know anything about. The Marfan Foundation has guided me through all of my concerns. They have given me all the support and information needed to advocate for my children [so they receive] proper treatment.

The Foundation has given me and thousands of other people, the peace of mind that they are working hard to better the lives of those affected."

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that research into heritable connective tissue disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

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The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

People with Marfan syndrome are born with it, but features of the disorder are not always present right away. Some people have a lot of Marfan features at birth or as young children – including serious conditions like aortic enlargement. Others have fewer features when they are young and don't develop aortic enlargement or other signs of Marfan syndrome until they are adults. Some features of Marfan syndrome, like those affecting the heart and blood vessels, bones or joints, can get worse over time.

This makes it very important for people with Marfan syndrome and related disorders to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications. The earlier some treatments are started, the better the outcomes are likely to be.

Knowing the signs of Marfan syndrome can save lives. Our community of experts estimates that nearly half the people who have Marfan syndrome don't know it. CDC and NCBDDD have critical programs that can help improve awareness and recognition of warning signs, which can save lives. Some of these programs including CDC's Million Hearts Campaign and NCBDDD's newborn screening activities. Meaningful funding increases will allow CDC and NCBDDD to expand their successful awareness efforts to include additional conditions.

NATIONAL INSTITUTES OF HEALTH

NIH has worked closely with the Foundation to investigate the mechanisms of these conditions. In recent decades, this research has yielded significant scientific breakthroughs that have the potential to improve the lives of affected individuals. In order to ensure that the heritable connective tissue disorders research portfolios can continue to expand and advance, NIH requires meaningful funding increases to invest in emerging and promising activities.

NHLBI
The Marfan Foundation anxiously await the results of this first-ever multicenter clinical trial for our patient population conducted by the National Heart, Lung and Blood Institute's Pediatric Heart Network (PHN). After four years of recruitment and three years of follow-up evaluations, the results are expected to be released in November 2014 at the American Heart Association Meeting. 604 Marfan syndrome patients (age 6 months to 25 years) are enrolled in the 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). The Marfan Foundation thanks both NHLBI and NIAMS for their dedicated support and careful execution of this trial.

NEI
Ectopia lentis, dislocation of the lens, occurs in up to 60 percent of patients with Marfan syndrome. The central positioning of the lens depends on the zonule of Zinn, a fibrous structure which has fibrillin-1 as a major component. NEI-supported investigators are studying the protein interactions of fibrillin-1 in health and disease in the zonule of Zinn to understand the disease mechanisms that cause ectopia lentis. It is hoped that this research will provide therapeutic insights to better treat this complication of Marfan syndrome.

NIAMS
NIAMS continues to support the Consortium for Translational Research in Marfan Syndrome, which is investigating the disease process in MFS. These studies, building on previous advances, are aimed at identifying new biological targets for therapy, as well as predictive biomarkers of vascular and skeletal manifestations, which are the major causes of mortality and morbidity in MFS.

ORDR
The National Center for Advancing Translational Sciences houses ORDR and leads other important activities. In addition to the Rare Disease Clinical Research Consortia, translational treatment development programs hold promise for the heritable connective tissue disorders community.

TESTIMONY OF
Vicki Kalabokes
President and CEO

ON BEHALF OF
The National Alopecia Areata Foundation (NAAF)
14 Mitchell Boulevard
San Rafael, CA 94903

REGARDING
Fiscal Year 2015 (FY15) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 28th Day of March, 2014

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- **$32 billion in program level funding for the National Institutes of Health (NIH)**.
  - Proportional funding increases for NIH's National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), National Institute of Allergy and Infectious Diseases (NIAID), and National Center for Advancing Translational Sciences (NCATS).

Chairman Kingston and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals affected by alopecia areata as you work to craft the FY15 L-HHS Appropriations Bill.

ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases; NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

DEIDRE'S STORY

It has been 15 years since I first found the bald patch on my head that would completely change the course of my life. As a student at Florida State University during my junior year I found a perfectly round bald patch while blow-drying my very thick long hair – my pride and joy! Little did I know then the significant effect alopecia areata would have on my life.

I followed the typical patient profile for this disease. I started with one patch the size of a 50 cent piece, which later evolved into patches of varying sizes all over my head, and then to total loss of all scalp hair, which progressed to the most severe form of the disease: total loss of all body hair including my scalp, eyebrows, eyelashes, etc. Recently, my hair has inexplicably started to grow back in a very patchy and strange fashion on my head, while most of my body still remains hairless; a perfect example of the completely unpredictable course of this disease, which can cause significant emotional turmoil and distress for the sufferer.

As a professional woman, this disease has had a severe impact on my life. I have to present a confident image to the outside world. Living in constant fear of being discovered as a bald woman, being thought to be sick, bizarre, or worse has always been on the forefront of my mind. The exorbitant cost for treatments such as cortisone injections, extremely painful with questionable efficacy, has been an issue for me along with the expensive cranial prosthetics. Over the course of the years these have cost me thousands of dollars. If a lawyer like myself has financial difficulty when it comes to paying for treatments and prosthetics (which are not covered by insurance due to lack of CMS coverage benefits for those with Alopecia Areata), can you imagine the plight facing those patients that live on limited or fixed income?

The fact that there is so little known about the causes or possible treatments/cure for this disease only adds to the pain and suffering. This is a disease that alters the way you see yourself and the way the outside world treats you, and also causes significant and often debilitating emotional distress. The fact that there is little that can currently be done adds to that pain and suffering. Patients face a bleak outlook. For me, it has been a constant battle. I have not lived a single moment in the 5,475 days since that I have not looked in the mirror and wanted to scream or cry, not a single day that I haven't thought that I am damaged, abnormal, or ugly because of my hair loss, not a single day that I haven't worried about how a client, colleague, friend, or love-interest might see and judge me. Many will say to me that "it is only hair" or "at least it's not cancer." These comments only frustrate and upset me more. The feelings of being ostracized as an outcast can become deafening, even for a confident, intelligent professional. I shudder to think how others who don't possess my strength of character handle the stresses of this disease.

It is only with additional funding for research that we might hope to improve the lives of the millions in the US living with alopecia areata. Few have even heard of the disease. That fact alone creates additional stresses and difficulties for those of us with the disease, constantly having to explain what is "wrong" with us. Increased research into viable treatment options and a

potential cure could significantly impact millions of lives, from small children to adults, facing the constant battle that comes from a total loss of self image and confidence.

I thank you on behalf of myself and of the entire alopecia areata community for consideration of NAAF's requests.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that research into alopecia areata, skin, and autoimmune disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in FY13 was $6 billion (22.4 percent) less than it was in FY03.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since FY03. In FY 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in FY03.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between FY03 and FY13.

The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC and NCCDPHP are well-positioned to improve our understanding of alopecia areata through surveillance and surveys. There are many opportunities in this area due to the fact that alopecia areata is the most easily observable autoimmune disease. Robust epidemiology could yield important information for all autoimmune diseases, not just alopecia areata. CDC requires a meaningful investment in FY15 so that it can expand its crucial public health activities beyond winnable battles.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation's TDP, have the potential to identify biomarkers and develop therapeutic targets. In fact, alopecia areata research has a strong value proposition as scientific advancements may have applications for other autoimmune and skin diseases. Please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

One exciting emerging opportunity is the new Accelerating Medicines Partnership (AMP) that was recently announced by NIH. This effort is outcomes-oriented and based on a public private-partnership model. Industry, patient organizations, and researchers work together to conduct research with the goals of improving treatments and diagnostic tools. Rheumatoid arthritis is one of the diseases being examined in the first round of study, which should generate opportunities for alopecia areata due to the similarities between the conditions. Please support AMP and encourage NIH to expand activities in this area, particularly when there is research overlap between conditions

ADDITIONAL ACTIVITIES

FDA nominated alopecia areata as a potential condition for specific review through the Patient-Focused Drug Development Initiative (PFDDI). This is because many of the impacts of alopecia areata have to be reported by patients and cannot be measured biologically. While we appreciate that FDA falls under the guise of the Agriculture Appropriations Subcommittee, we ask that you work with your colleagues on the Appropriations Committee to support this important program. Further, FDA should be encouraged to review all originally-nominated conditions in a timely manner so the PFDDI can continue to move forward.

Thank you for your time and your consideration of the community's requests.

TESTIMONY OF
Mr. Rino Aldrighetti
President and CEO

ON BEHALF OF
The Pulmonary Hypertension Association (PHA)
801 Roeder Rd, Suite 1000
Silver Spring, MD 20910

REGARDING
Fiscal Year 2015 (FY15) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

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The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 28th Day of March, 2014

THE ASSOCIATIONS'S FY15 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**

- **$7 billion in program in discretionary budget authority for the Health Resources and Services Administration (HRSA).**

- **$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
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Chairman Kingston and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the pulmonary hypertension community as you work to craft the FY15 L-HHS Appropriations Bill.

ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition simply described as high blood pressure in the lungs. It affects people of all ages, races and ethnic backgrounds. Although anyone can get PH, there are risk factors that make some people more susceptible.

Treatment and prognosis vary depending on the type of PH. In one type, pulmonary arterial hypertension (PAH), the arteries in the lungs become too narrow to handle the amount of blood that must be pumped through the lungs. This causes several things to happen: a backup of blood in the veins returning blood to the heart; an increase in the pressure that the right side of your heart has to pump against to push blood through your lungs; and a strain on the right side of your heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of your heart can become overworked, become very weak and may possibly fail. Because the blood has difficulty getting through the lungs to pick up oxygen, your blood oxygen level may be lower than normal. This can put a strain not only on your heart, but also decrease the amount of oxygen getting to your brain.

There is currently no cure for PAH. Twelve treatment options are available to help patients manage their disease and feel better day to day but even with treatment, life expectancy with PAH is limited.

ABOUT THE ASSOCIATION

From simple beginnings – four women who met around a kitchen table in Florida in 1990 – the Pulmonary Hypertension Association has evolved into a community of well over 10,000 pulmonary hypertension patients, caregivers, family members and medical professionals.

As we have grown, we have stayed true to our roots and the vision and ingenuity of our founders: *We continue to work every day to end the isolation that PH patients face, and find a cure for pulmonary hypertension.*

Research

PHA provides grants to promising researchers in the field of pulmonary hypertension. The program fosters new leaders in the field by supporting their interest in PH research and providing them with opportunities to work with mentors and learn new skills. Researchers supported by PHA are looking for new methods for early detection, new treatments to prevent the onset of PH and ultimately a cure for this terrible illness. To date, PHA has leveraged more than $13 million in PH research funding through partnerships with the NIH and others.

Early Diagnosis Campaign
It takes too long for pulmonary hypertension to be diagnosed. The median survival rate without treatment is approximately 2.8 years, making the need to obtain a rapid and accurate diagnosis urgent. Unfortunately, the median duration from symptom onset to a confirmed diagnosis by right heart catheterization is 1.1 years. We are reaching patients too late in the process. Almost three-fourths of patients have advanced PH by the time they are diagnosed, leading more costly treatments and poorer outcomes. For the most advanced cases of PH, a lung or heart-loung transplant may be the only treatment option. The goal of PHA's Early Diagnosis Campaign is to discover the disease sooner in the early stages. This will allow the start of a treatment regimen that can slow the progression of PH and secure a better life for the patient.

Center Accreditation
The Pulmonary Hypertension Association's Scientific Leadership Council, 28 global leaders in the field of pulmonary hypertension, have spearheaded the PHA-Accredited PH Care Centers (PHCC) initiative. The goal of this initiative is to establish a program for accreditation of centers with special expertise in pulmonary hypertension (PH), particularly pulmonary arterial hypertension (PAH), to raise the overall quality of care and outcomes in patients with this life-threatening disease.

ONE PATIENT'S STORY

In 2011, at the age of 29, GS12 Human Terrain Analyst Jessica (Puglisi) Armstrong began experiencing shortness of breath and dizziness. She was in Afghanistan at the time. Jessica was first diagnosed with dehydration. Then, as is the case with many PH patients, she was told she had asthma and was given an inhaler. Two months later, she fainted for no apparent reason. An echocardiogram revealed blood clots in her lungs and Jessica was medically evacuated to Germany and then to the U.S. Six months after her fist symptoms, she was finally given a complete work up and diagnosed with pulmonary hypertension.

Jessica, she had a unique form of PH due to blood clots that can be mitigated with a pulmonary thromboendarterectomy (PTE) – a complex surgery that involves opening the chest cavity and stopping circulation for up to twenty minutes. She describes the surgery, which she underwent at the University of California San Diego, as "more painful than I could ever imagine." She notes that UCSD's PTE program did not begin until 1990 and even now, despite being recognized as the global leaders on this procedure, has only completed about 3,000 surgeries. The procedure that saved Jessica's was developed in her lifetime.

Jessica was terminated from Army employment and spent $60,000 out of pocket on medical expenses which she has not been able to recoup. She was forced to begin a civilian job just two weeks after her PTE in order to retain health insurance. Despite this, Jessica is, in many ways, one of the lucky ones. I am glad to report that she is now doing well and serving an integral role at PHA as the coordinator of our Early Diagnosis Campaign.

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. 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.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that the pulmonary hypertension research portfolio can continue to grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. The Association has anecdotal accounts of the harms of sequestration and the Federated American Societies for Experimental Biology has reported:

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The pay line for some NIH funding mechanisms has fallen from 18% to 10% while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next five years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Association asks that you work with your colleagues to eliminate sequestration and recommit to supporting this nation's biomedical research enterprise.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. Federal organ transplantation activities are coordinated through HRSA. To ensure HRSA can expand its important mission and continue to make improvements in donor lists and donor-matching please provide HRSA with a meaningful funding increase in FY 2015.

CENTERS FOR DISEASE CONTROL AND PREVENTION

As a result of federal investment in medical research, there are now twelve FDA-approved treatments for PH. The effectiveness of these therapies though is dependent on how early a patient can receive an accurate diagnosis and begin treatment. Unfortunately, two-thirds of patients are not diagnosed until PH has reached a late stage. In addition to mitigating the impact of many treatments, late diagnosis puts PH patients in a position to face interventions like heart-lung transplantation and even death. CDC and NCCDPHP have the resources to compliment

PHA's own *Sometimes its PH* Early Diagnosis Campaign. Improving public awareness and recognition of PH will not only save lives, it can save the federal healthcare system money. Please provide CDC with meaningful funding increases so the agency can expand its focus beyond winnable battles into increasingly important and cost-effective areas.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a sizable PH research portfolio. Further, NIH and PHA have a strong track record of working together to advance our scientific understanding of PH. The twelve FDA-approved treatments, more than nearly every other rare disease, are evidence of the return-on-investment from these activities. Please provide NIH with meaningful increases to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment.

Comment [KK1]: There is a specific number on the front page, do we want a specific number here?

NCATS
The Office of Rare Diseases Research (ORDR), located within NCATS, supports and coordinates rare disease research and provides information on rare diseases to patients, their families, healthcare providers, researchers and the public. In collaboration with other NIH institutes, ORDR funds rare diseases research primarily through the Rare Diseases Clinical Research Network (RDCRN), which supports clinical studies, investigator training, pilot projects, and access to information on rare diseases. The most recent funding opportunity announcement, which was widely broadcast and open to all rare diseases, including PAH, was issued in the fall of 2013 and awards are expected to be made in the summer of 2014

NHLBI
The NHLBI-funded Centers for Advanced Diagnostics and Experimental Therapeutics in Lung Diseases Stage II program, which will begin in FY 2014, will provide a mechanism to accelerate the development of therapies for lung diseases, including pulmonary fibrosis and pulmonary arterial hypertension.

ADDITIONAL ACTIVITIES

H.R. 2073
Congressman Kevin Brady (R-TX) and Congresswoman Lois Capps (D-CA) have introduced the *Pulmonary Hypertension Research and Diagnosis Act* (H.R. 2073). This budget neutral legislation is supported by members of the House Ways and Means Committee for its emphasis on lowering healthcare costs by promoting efficiencies within the federal government. H.R. 2073 seeks to establish an HHS-wide Committee tasked with preparing a report on how to leverage limited resources to improve early diagnosis of PH. Please consider cosponsoring H.R. 2073 and working with your colleagues to advance this important legislation.

TESTIMONY OF
Mr. Robert J. Riggs
Chief Executive Officer

ON BEHALF OF
The Scleroderma Foundation (SF)
300 Rosewood Drive, Suite 105
Danvers, MA 01923

REGARDING
Fiscal Year 2015 (FY15) appropriations for medical research and public health programs funded annually through the Labor, Health and Human Services, Education, and Related Agencies (L-HHS) Appropriations Bill

SUBMITTED TO
The House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

ON
The 28th Day of March, 2014

THE FOUNDATION'S FY15 L-HHS APPROPRIATIONS RECOMMENDATIONS

- **Continue working to eliminate sequestration so that non-defense discretionary programs do not face uncertainty and challenging funding reductions.**

- **$7.8 billion in program level funding for the Centers for Disease Control and Prevention (CDC)**, which includes budget authority, the Prevention and Public Health Fund, Public Health and Social Services Emergency Fund, and PHS Evaluation transfers.
  - A proportional FY2015 funding increase for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

- **$32 billion in program level funding for the National Institutes of Health (NIH)**.
  - Proportional funding increases for NIH's National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); National Institute of Allergy and Infectious Diseases (NIAID); National Center for Advancing Translational Sciences (NCATS).

Chairman Kingston and distinguished members of the Subcommittee, thank you for your time and your consideration of the scleroderma community's priorities while working to craft the FY15 L-HHS Appropriations Bill.

ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases.

The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called "progressive systemic sclerosis," but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient.

It is estimated that about 300,000 Americans have scleroderma. About one third of those people have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult. There may be many misdiagnosed or undiagnosed cases.

Localized scleroderma is more common in children, whereas systemic scleroderma is more common in adults. Overall, female patients outnumber male patients at a ratio of 4-to-1. Factors other than gender, such as race and ethnic background, may influence the risk of getting scleroderma, the age of onset, and the pattern or severity of internal organ involvement. The reasons for this are still unknown. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic or autoimmune diseases. While, scleroderma can develop in every age group from infants to the elderly, its onset is most frequent between the ages of 25 to 55.

Currently, there is no cure for scleroderma. Treatments are based on a patient's particular symptoms. For instance, heartburn can be controlled by medications called proton pump inhibitors or medicine to improve the motion of the bowel. Some treatments are directed at decreasing the activity of the immune system. Due to the fact that there is so much variation from one person to another, there is great variation in the treatments prescribed.

Any chronic disease can be serious. The symptoms of scleroderma vary greatly for each person, and the effects of scleroderma can range from mild to life threatening. The seriousness will depend on which organ systems of the body are affected, and the extent to which they are affected. A mild case can become more serious if not properly treated. Prompt and proper diagnosis and treatment by qualified physicians may minimize the symptoms of scleroderma and lessen the chance for irreversible damage.

ABOUT THE FOUNDATION

The non-profit Scleroderma Foundation is the national organization for people with scleroderma and their families and friends. It was formed January 1, 1998, by a merger between the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation.

The national office is headquartered in Danvers, Massachusetts. The Foundation has a three-fold mission of support, education, and research.

Support
The Scleroderma Foundation offers the following tools and resources in support of people living with scleroderma and their families:

- A nationwide network of 24 chapters and more than 150 support groups
- A toll-free helpline providing information and referrals to callers
- Educational materials, including a quarterly magazine called "Scleroderma Voice"
- Offer a variety of brochures, booklets and newsletters, along with our informative website

Additionally, the Foundation hosts an annual National Patient Education Conference. The conference offers various educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends. Workshops, panel discussions and other educational sessions are led by the leading scleroderma researchers and healthcare professionals.

Education
As part of our education mission, we not only perform all the functions mentioned above, we also work with our Medical Advisory Board of internationally known scleroderma experts to provide patient education programs as well as education for physician/healthcare professionals.

Research
The Scleroderma Foundation budgets at least $1 million a year for research funding, its single largest budgeted expense. The Scleroderma Foundation takes its fiduciary responsibility to donors very seriously, especially with regard to our research grant program.

In the case of research funds, the Foundation's Peer Research Review Committee, composed of medical experts on scleroderma from around the world, helps determine which proposals will be funded by reading, analyzing and ranking all proposals received. It follows a peer review system based on that of the National Institutes of Health.

ONE FAMILY'S STORY
Cheyenne Cogswell is an eight-year old third-grader living in the poverty-stricken town of Falmouth, Kentucky. Cheyenne was diagnosed at age six with a severe case of systemic scleroderma. The disease has caused kidney failure and significant damage to her digestive system, making it difficult for the body to receive the proper nutrition needed for a growing child. She has undergone several life-saving operations and numerous hospitalizations. Her skin and other internal organs, such as the heart and lungs, are also affected. Cheyenne's treatment first consisted of hospitalization and intense chemotherapy. She continues with daily chemotherapy injections, now given by her mother, to help suppress her immune system and slow the progression of the disease. Cheyenne is being raised by a single mother who has faced extreme consequences from the financial burden created by scleroderma, losing her job in the economic downturn, as well as the family's home. Doctors doubted if Cheyenne would survive

beyond her seventh birthday, but she continues to beat the odds. Chronic diseases like scleroderma are unpredictable in their course, and the family – together with their close circle of friends – continues to fight and hope for the best. Their road is uncertain and illustrates why funding for NIH and its research programs are vital to so many people whose lives are impacted by chronic illness such as scleroderma.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for federal funding opportunities and the career development pipeline. In order to ensure that the scleroderma research portfolio can continue to grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

- In constant dollars (adjusted for inflation), the NIH budget in FY13 was $6 billion (22.4 percent) less than it was in FY03.
- The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since FY03. In FY 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in FY03.
- Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between FY03 and FY13.

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CENTERS FOR DISEASE CONTROL AND PREVENTION

Early recognition and an accurate diagnosis of scleroderma can improve health outcomes and save lives. CDC in general and the NCCDPHP specifically have programs to improve public awareness of scleroderma and other rare, life-threatening conditions. Unfortunately, budgetary challenges at CDC have pushed the agency to focus resources on combating a narrow set of "winnable battles." Please increase funding for CDC and NCCDPHP so that the agency can invest in additional, critical education and awareness activities that have the potential to improve health and save lives.

NATIONAL INSTITUTES OF HEALTH

NIH has worked with the Foundation to lead the effort to enhance our scientific understanding of the mechanisms of scleroderma with the shared-goal of improving diagnosis and treatment, and ultimately finding a cure. Since scleroderma impacts multiple organ systems, NIAMS, NHLBI, and NIDDK all play crucial roles in basic, translational, and clinical research efforts. Further, emerging NIH initiatives like the Cures Acceleration Network and the Accelerating Medicines Partnership are creating meaningful opportunities to advance scleroderma research. Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

- NHLBI, is leading Scleroderma Lung Study II, is comparing the effectiveness of two drugs in treating pulmonary fibrosis in scleroderma.
- NIAMS, is leading efforts to discover whether three gene expression signatures in skin can serve as accurate biomarkers predicting scleroderma, and investigations into progression and response to treatment to clarify the complex interactions of T cells and interleukin-31 (IL-31) in producing inflammation and fibrosis, or scarring in scleroderma.

ADDITIONAL MEDICAL RESEARCH ACTIVITIES

In recent years, scleroderma has been listed as a condition eligible for study through the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP). Since FY05, the opportunity for scleroderma researchers to compete for funding through this mechanism led to over $10 million in scleroderma research funding as well as the initiation of meaningful research projects. Research on the underlying mechanisms of scleroderma is showing relevance to all fibrosis, which occurs at higher rates among individuals who served in the military and our veterans. Further, military service-associated environmental triggers, particularly silica, solvent, and radiation exposure, are believed to be potential triggers for scleroderma in individuals that are genetically predisposed to it.

Despite the connection between military service and scleroderma, the condition was left off the PRMRP's eligible conditions list in FY14. While we appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list, the scleroderma community urges you to weigh in with your colleagues on the Appropriations Committee to actively work to see that scleroderma is re-listed as a condition eligible for study through the PRMRP within the Committee Report accompanying the FY15 Defense Appropriations Bill.

Thank you again for your time and your consideration of the scleroderma community's requests.

THE AMERICAN SOCIETY OF NEPHROLOGY

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES SUBCOMMITTEE OF THE UNITED STATES HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

WRITTEN TESTIMONY IN SUPPORT OF INCREASED FUNDING FOR THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES AT THE NATIONAL INSTITUTES OF HEALTH

MARCH 28, 2014

The American Society of Nephrology (ASN) is the world's largest kidney health professional organization in the world, representing 15,000 physicians, other healthcare providers, and scientists, and committed to advancing research, prevention, and treatment options for the more than 20 million adults, children, and adolescents with kidney disease in the United States today. The society requests at least $2.066 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH). The society also requests an additional $150 million/year over 10 years for kidney research above current funding for NIDDK.

ASN believes these are crucial and necessary investments for preventing illness and maintaining fiscal responsibility. Investing in research to slow the progression of kidney

disease and identify new therapies will save Medicare spending for the End-Stage Renal Disease (ESRD) Program in the long run.

In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare ESRD Program—the only health entitlement program that provides coverage regardless of age or disability. Today, ESRD patients account for less than 1% of the Medicare population but 7% of the Medicare budget. Meanwhile, at approximately $650 million per year, total federal funding for kidney research is equivalent to less than 1% of the nearly $77 billion Medicare spends annually for the care of patients with kidney disease.

Given that the Medicare ESRD Program is unique in that it covers treatment for all patients with kidney failure regardless of age or disability, preventing kidney disease and improving therapy—starting with innovative research at NIDDK—would yield significant savings to the Centers for Medicare and Medicaid Services.

The vast majority of federal research leading to advances in the care and treatment of patients with kidney disease is funded by NIDDK. Examples of critical discoveries arising from NIDDK-funded research are numerous.

For instance, investigative studies supported by NIDDK led to a groundbreaking discovery that helps explain racial and ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and treatment. The finding that African

Americans with two variants of the APOL1 gene are likely to progress to kidney failure faster than other ethnicities paves the way for future research to unlock better preventive therapies and gene-based cures.

Recent findings from NIDDK's Chronic Renal Insufficiency Cohort (CRIC) Study led to the discovery that the progression of kidney disease is associated with less efficient pumping of blood by the heart. Further research exploring the mechanisms for this development could lead to new interventions that could slow down the progression of kidney disease.

Scientists supported by NIDDK have pursued cutting-edge basic, clinical, and translational research. While ASN fully understands the difficult economic environment, the society firmly believes that funding NIDDK is a sound investment to create jobs, support the next generation of investigators, and ultimately provide quality care that is less expensive in order to improve the public health of Americans.

Medical research is a major force in the economic health of communities nationwide: every dollar invested in medical research generates $2.60 in economic activity. America must continue to capitalize on previous investments to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and maintain leadership in the global innovation economy—particularly as other countries increase their investments in scientific research. Most important, a failure to maintain and strengthen NIDDK's ability to support the groundbreaking work of researchers

across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

ASN urges Congress to uphold its longstanding legacy of bipartisan support for biomedical research. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact ASN Manager of Policy and Government Affairs Rachel Meyer at (202) 640-4659 or rmeyer@asn-online.org.

ABOUT ASN

The American Society of Nephrology (ASN) is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's 15,000 physicians, scientists, and other healthcare professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients. For more information, visit ASN's website at www.asn-online.org.

To: U.S. House Subcommittee on Labor, HHS, Education and Related Agencies Appropriations
From: Dr. Lisa Simpson, President & CEO, AcademyHealth
Re: FY 2015 Funding for Health Services Research & Health Data at AHRQ, NCHS, NIH

AcademyHealth is pleased to offer this testimony regarding funding for federal agencies that support health services research and health data, including the Agency for Healthcare Research and Quality (AHRQ), the National Center for Health Statistics (NCHS), and the National Institutes of Health (NIH). AcademyHealth's mission is to support research that leads to accessible, high value, high-quality health care; reduces disparities; and improves health. We represent the interests of more than 5,000 scientists and policy experts and 180 organizations that produce and use health service research to improve our nation's health and the performance of the health care and public health systems. For FY 2015, we recommend funding levels of $375 million for AHRQ, $182 million for NCHS, and $32 billion for NIH.

The United States spent $2.8 trillion—17.2 percent of our economy—on health care in 2012. Finding new ways to get the most out of every health care dollar is critical to our nation's long-term fiscal health. Like any corporation making sure it is developing and providing high quality products, the federal government—as the nation's largest health care purchaser—has a responsibility to get the most value out of every taxpayer dollar it spends on Medicare, Medicaid, Children's Health Insurance Program, and veterans' and service members' health.

Health services research is our nation's R&D enterprise for health improvement. Just as medical research discovers cures for disease, health services research discovers cures for the health system (see Figure 1). This research diagnoses problems in health care and public health delivery and identifies solutions to improve outcomes for more people, at greater value. And while biomedical and clinical research discoveries can take years and even decades to reach

patients, discoveries from health services research can be used now by patients, health care providers, public health professionals, hospitals, employers, and public and private payers to improve care today.

Put plainly, health services research helps Americans get their money's worth when it comes to health care. We need more of it, not less. Despite the positive impact health services research has had on the U.S. health care system, and the potential for future improvements in quality and value, the United States spends less than one cent of every health care dollar on this research; research that can help Americans spend their health care dollars more wisely and make more informed health care choices.

AcademyHealth realizes the pressure Congress and the administration face to reduce the national debt. We respectfully ask that the subcommittee consider the value of health services research in achieving that goal, and to strengthen its capacity to address the pressing challenges America faces in providing access to high-quality, efficient care. The following list summarizes AcademyHealth's FY 2015 funding recommendations for agencies that support health services research and health data under the subcommittee's jurisdiction.

Agency for Healthcare Research and Quality

AHRQ is the only federal research agency with the sole purpose of producing evidence to make health care safer; higher quality; more accessible, equitable, and affordable; and to ensure that the evidence is understood and used. AHRQ funds health services research and health care improvement programs in universities, medical centers, research institutions, hospitals, health clinics, and medical practices that are transforming people's health in communities in every state around the nation. The science funded by AHRQ provides consumers and their health care professionals with valuable evidence to make health care decisions. For example, medical

societies use AHRQ-funded research to inform their recommendations for treatment of type 2 diabetes and rheumatoid arthritis. These evidence-informed recommendations give physicians a foundation for describing what the best care looks like, so millions of patients living with these and other conditions may determine what the right care might be for them.

AHRQ's research also provides the basis for strategies that prevent medical errors, reduce hospital-acquired infections (HAI), and improve patient experiences and outcomes. For example, AHRQ's evidence-based Comprehensive Unit-based Safety Program to Prevent Healthcare-Associated Infections (CUSP)—first applied on a large scale in 2003 across more than 100 ICUs across Michigan—saved more than 1,500 lives and nearly $200 million in the program's first 18 months. The protocols have since been expanded to hospitals in all 50 states, the District of Columbia, and Puerto Rico to continue the national implementation of this approach for reducing HAIs.

AcademyHealth joins the Friends of AHRQ—an alliance of health professional, research, consumer, and employer organizations that support the agency—in recommending a base discretionary funding level of $375 million for AHRQ in FY 2015.

National Center for Health Statistics

NCHS is the nation's principal health statistics agency. Housed within the Centers for Disease Control and Prevention (CDC), it provides critical data on all aspects of our health care system through data cooperatives and surveys that serve as a gold standard for data collection around the world. AcademyHealth appreciates the subcommittee's support of NCHS in recent years. Such efforts have allowed NCHS to reinstate data collection and quality control efforts,

continue the collection of vital statistics, and modernize surveys to reflect changes in demography, geography, and health delivery.

We join the Friends of NCHS—an alliance of health professional, research, consumer, industry, and employer organizations that support the agency—in recommending an overall funding level of $182 million for NCHS in FY 2015. This funding level will support the agency's core data collection activities, as well as new initiatives to enhance death data timeliness and security, restore survey expansions to better assess access to and utilization of health care services, and determine "what works" in the organization, financing, and delivery of public health services.

National Institutes of Health

NIH spends approximately $1 billion on health services research annually—roughly 3 percent of its entire budget—making it the largest federal sponsor of health services research. We join the research community in seeking at least $32 billion for NIH in FY 2015. NIH has an important role in the federal health services research continuum, and is well-positioned to ensure that discoveries from clinical trials are effectively translated into health care delivery. AcademyHealth supports efforts to help NIH foster greater coordination of its health services research investment among its institutes and across other federal agencies to avoid duplication.

AcademyHealth also recommends that the Clinical and Translational Science Awards (CTSA) through the National Center for Advancing Translational Sciences (NCATS) sustain investment in the full spectrum of translational research (T1-T4). The CTSA program enables innovative research teams to speed discovery and advance science aimed at improving our nation's health. The program encourages collaboration in solving complex health and research challenges and finding ways to turn their discoveries into practical solutions for patients.

Finally, AcademyHealth supports continued investment by NIH and its many Institutes and Centers in dissemination and implementation research. This research helps us understand which approaches work to improve population health.

In conclusion, the accomplishments of the field of health services research would not be possible without the leadership and support of this subcommittee. We hope the subcommittee gives strong consideration to our FY 2015 funding recommendations for the federal agencies funding health services research and health data. If you have questions or comments about this testimony or wish to know more about health services research, please contact Dr. Lisa Simpson, President and CEO of AcademyHealth, at 202.484.1100 or lisa.simpson@academyhealth.org.

Figure 1: The Health Research Continuum

These components of the health research continuum work in concert, and each plays an essential role—any one type of research on its own cannot effectively or appreciably improve health. Take heart disease as one example...

Basic research discovered the contributions of elevated blood pressure, elevated cholesterol, and tobacco use to heart disease.	**Clinical research** determined which treatments were safe and effective to treat hypertension, hypercholesterolemia, tobacco addiction, and to prevent and treat heart disease, in general.	**Population-based research** identified strategies to reduce the risks of heart disease in communities through non-medical interventions, such as reduction of trans fats in food and tobacco control measures to reduce smoking.	**Health services research** determined how to best deploy these discoveries to achieve the best health outcomes. This research helped identify who had the least access, what barriers existed, and how to mitigate them. This research also led to the development of quality measures that are now used to report on the quality of cardiac care.

Source: *AHRQ: 15 Years of Transforming Care and Improving Health,* AcademyHealth, Jan. 2014. Available at: http://academyhealth.org/files/AHRQReport2014.pdf

Written Testimony of the Emergency Nurses Association (ENA)
Fiscal Year (FY) 2015 Appropriations
House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Submitted by 2014 ENA President Deena Breeher, MSN, RN, APN, ACNS-BC, CEN, CPEN
March 28, 2014

The Emergency Nurses Association (ENA), with more than 40,000 members worldwide, is the only professional nursing association dedicated to defining the future of emergency nursing and emergency care through advocacy, expertise, innovation, and leadership. Founded in 1970, ENA develops and disseminates education and practice standards and guidelines, and affords consultation to both private and public entities regarding emergency nurses and their practice. ENA has a great interest in the work of the House Labor, Health and Human Services, Education Subcommittee and especially its efforts to improve the quality of emergency care for patients in the United States. For fiscal year 2015, ENA respectfully requests $28 million for Trauma and Emergency Care Programs (HHS; HRSA), $251 million for Nursing Workforce Development programs (HHS; HRSA), $21.116 million for the Emergency Medical Services for Children program (HHS; HRSA), $30.1 million to fund poison control centers (HHS; HRSA), $150 million for the National Institute of Nursing Research (HHS; NIH), and $8.927 million for Rural Health – Access to Emergency Devices (HHS; HRSA).

Trauma and Emergency Care Programs

Trauma is the leading cause of death for persons younger than 44 and the fourth-leading cause of death for all ages. In states with an established trauma system, patients are 20 percent more likely to survive a traumatic injury. Victims of traumatic injury treated at a Level I trauma center are 25% more likely to survive than those treated at a general hospital.

Our trauma and emergency medical systems are designed to transport seriously injured individuals to trauma centers quickly. However, due to a lack of financial resources, 45 million

Americans do not have access to a major trauma center within the "golden hour" following an injury when chances of survival are highest.

Trauma and emergency care programs, which are authorized under the Public Health Service Act, provide much-needed money to the states to develop and enhance of their trauma systems. These programs are critical to the efficient delivery of services through trauma centers, as well as to the development of regionalized systems of trauma and emergency care that ensure timely access for injured patients to appropriate facilities. This modest investment can yield substantial returns in terms of cost efficiencies and, most importantly, saved lives.

Therefore, the ENA respectfully requests $28 million in FY 2015 for trauma and emergency care programs.

Nursing Workforce Development Programs

The nursing profession faces significant challenges to ensure that there will be an adequate number of qualified nurses to meet the growing healthcare needs of Americans. It is estimated that 80 million Baby Boomers turned 65 last year. This growing elderly population will seek healthcare services in a multitude of settings and the care they require requires a highly educated and skilled nursing workforce. A 2014 projection from the U.S. Bureau of Labor Statistics' *2013-2014 Employment Outlook Handbook* anticipates that the number of practicing RNs will grow 19 percent by 2022.

The aging of the Baby Boom generation will deplete the nursing ranks as well. During the next 10 to 15 years, approximately one-third of the current nurse workforce will reach retirement age. The retirement of these experienced nurses has the potential to create a serious deficit in the nursing pipeline. At the same time, our colleges cannot keep up with the demand for new nurses. According to the American Association of Colleges of Nursing's (AACN)

2013-2014 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing survey, 78,089 qualified applications were turned away from nursing schools in 2013 alone.

Title VIII Nursing Workforce Development programs address these factors and help support the training of qualified nurses. They not only enhance nursing education at all levels, from entry-level to graduate study, but they also support nursing schools that educate nurses for practice in rural and medically underserved communities. Another important part of Title VIII is the Faculty Loan Program which is critical to alleviating the large shortage in nursing faculty. Overall, more than 80,000 nurses and nursing students were trained and educated last year with the help of Title VIII nursing workforce development programs.

Therefore, the ENA respectfully requests $251 million in FY 2015 for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act.

Emergency Medical Services for Children

The Emergency Medical Services for Children (EMSC) program is the only federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure state-of-the-art emergency medical care for ill and injured children or adolescents; that pediatric services are well integrated into an EMS system backed by optimal resources; and that the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

The federal investment in the EMSC program produces a wide array of benefits to children's health through EMSC State Partnership Grants, EMSC Targeted Issue Grants, the Pediatric Emergency Care Applied Research Network, and the National EMSC Data Analysis Resource Center.

Therefore, the ENA respectfully requests $21.116 million in FY 2015 for the EMSC program.

Poison Control Centers

Poisoning is the second most common form of unintentional death in the United States. In 2009, 31,768 deaths nationwide were attributed to unintentional poisoning. Children are especially vulnerable to injury by poisoning and each day 300 children are treated for poisoning in emergency departments across the country and two die.

The nation's 56 poison control centers handle 3.4 million calls each year, including approximately 680,000 calls from nurses and doctors who rely on poison centers for an immediate assessment and expert advice on poisoning cases.

Not only are American's network of poison centers invaluable for treating victims of poisonings, but the work of the centers also results in substantial savings to our healtheare system. About 90 percent of people who call with poison emergencies are treated at home and do not have to visit an emergency department. In more severe poisoning cases, the expertise provided by poison control centers can decrease the length of hospital stays. It has been estimated that every dollar spent on America's poison control centers saves $13.39 in health care costs and lost productivity. The positive impact to the federal budget is also significant. A 2012 study by the Lewin Group found that poison control centers resulted in $313.5 million in savings to Medicare and $390.2 million in savings to Medicaid.

Therefore, the ENA respectfully requests $30.1 million in FY 2015 for poison control centers

The National Institute of Nursing Research (NINR)

As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR's mission is to promote and improve the health of individuals, families, communities, and populations. The Institute supports and conducts clinical and basic research and research training on health and illness across the

lifespan to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care.

NINR nurse-scientists examine ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation. Our country must look toward the prevention as a way of reducing healthcare expenditures and improving outcomes. The work of NINR is an important part of this effort.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse-researchers, many of whom also serve as faculty in our nation's nursing schools.

Therefore, the ENA respectfully requests $150 million in FY 2015 for the NINR.

Rural and Community Access to Emergency Devices Program

Fewer than 10 percent of people who suffer a cardiac arrest outside of a hospital setting survive. According to a 2011 study published in the New England Journal of Medicine, immediate CPR and prompt defibrillation using an automated external defibrillator (AED) can more than double a patient's chance of survival.

The Health Resources and Services Administration (HRSA)'s Rural and Community Access to Emergency Devices Program saves lives of patients with cardiac arrest. Between August 1, 2008, and July 31, 2010, nearly 800 cardiac arrest victims were reportedly saved through this program. Funding for this initiative is used to buy automated external defibrillators (AEDs), put AEDs in public places where cardiac arrests are likely to happen, and instruct lay rescuers and first responders in their use. Between March 1, 2010, and Feb. 28, 2011, 3,928 AEDs were placed and 28,776 people were trained in their use.

Therefore, the ENA respectfully requests $8.927 million in FY 2015 for the Rural and Community Access to Emergency Devices Program.

Testimony to the House Labor, Health and Human Services, Education and Related Agencies Subcommittee

Submitted on behalf of CAEAR Coalition:

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On behalf of the tens of thousands of individuals living with HIV/AIDS to whom members of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition provide care, I thank Chairman Rogers and Subcommittee Chairman Kingston and Ranking Member Lowey and Subcommittee Ranking Member DeLauro for affording us the opportunity to submit testimony regarding increased funding for the Ryan White HIV/AIDS Program.

The Communities Advocating Emergency AIDS Relief (CAEAR) Coalition is a national membership organization which advocates for sound federal policy, program regulations, and sufficient appropriations to meet the care, treatment, support service and prevention/wellness needs of people living with HIV/AIDS and the organizations that serve them, focusing on ensuring access to high quality health care and the evolving role of the Ryan White HIV/AIDS Program.

A Wise Investment in a Program That Works

The Ryan White HIV/AIDS Program works and demonstrates its essential role in securing the health of thousands of low-income, uninsured and underinsured people living with HIV/AIDS. In its Program Assessment Rating Tool (PART), the White House Office of Management and Budget (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% of all federal programs—the Ryan White HIV/AIDS Program was one of seven that received a score of 100% in "Program Results and Accountability."**

The Patient Protections and Affordable Care Act (ACA) is being implemented in states and jurisdictions across the United States. The impact of ACA coverage and the ways in which the Ryan White HIV/AIDS Program will need to integrate and compliment public and private health insurance coverage is still a work in progress. Until ACA implementation is more uniform and systems integration is complete, Ryan White will continue to serve 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 with HIV disease 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.
- The AIDS Drug Assistance Program (ADAP) in Part B provides life-saving, urgently needed medications to people living with HIV/AIDS in all 50 states and the territories.
- Part C provides grants to 444 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 where Part C funded clinics provide the only HIV specific medical services available in the region.
- 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 11 regional centers and 130 local community sites with coverage in all 50 states.

CAEAR Coalition's FY 2015 funding requests for Part A, Part B base and ADAP, and Part C reflect the amounts authorized by Congress in the most recent authorization of the program.

There continues to be an increasing gap between the number of people living with HIV/AIDS in the U.S. in need of care and the federal resources available to serve them. Between 2001 and 2009 the number of people living with AIDS grew 44% and yet funding for medical care and support services in communities with the greatest burden of HIV disease grew less than 12% between 2001 and 2011.

Similarly, funding for Part C–funded, faith and community-based primary care clinics, which provide medical care for people living with HIV/AIDS in remote, rural and geographically isolated, urban communities nationwide, grew by only 11% between 2001 and 2012 as the number of people they care for grew by 52%. The authorized amounts we request would not fully address these funding deficiencies, but would begin to reduce the still growing gaps in funding.

We thank you in advance for your consideration of our comments and our request for:

- $686.7 million for Part A to support grants to the cities where most people with HIV/AIDS live and receive their care and treatment.
- $427.5 million for Part B base to provide additional needed resources to the states to bolster the public health response statewide regardless of location.
- $943.3 million in funding for the AIDS Drug Assistance Program (ADAP) line item in Part B so uninsured and underinsured people with HIV/AIDS can access the anti-HIV and other prescribed medications they need to survive and insurance premiums, co-pays and co-insurance costs for treatment can be supported.
- $225.1 million for Part C to support grants to faith- and community-based organizations, health care agencies, and clinics.

- $34.5 million to fund the 11 regional centers funded under by Part F AETC to offer specialized clinical education and consultation to frontline providers.

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% nationally and by up to 75 % in some locations. The programs supported by the Ryan White HIV/AIDS Program also have been critical in reducing AIDS mortality by 70 %. The Ryan White Program works, resulting in both economic stimulus and social savings by keeping people healthy and productive.

Growing Needs as More Tested and Entering Care
The Centers for Disease Control and Prevention (CDC) estimates that as of 2008 there were 1,178,350 persons living with HIV/AIDS in the U.S. This represents an increase of approximately 7% from the previous estimate in 2006. Among persons initially diagnosed with HIV infection during 2008, one-third (33%) received an AIDS diagnosis within 12 months. These late diagnoses represent missed opportunities for treatment and prevention.

The FY 2015 appropriation presents a crucial opportunity to provide the Ryan White Program with the levels of funding needed to address a growing epidemic in young men, as the CDC continues to increase efforts to expand HIV testing so people living with HIV know their status, control their health, and protect others.

CAEAR Coalition supports efforts to help individuals infected with HIV learn their status at the earliest possible time. The White House HIV Care Continuum Initiative is focused on improving the health outcomes and well being for people living with HIV by ensuring that more individuals are tested and identified as HIV positive, then linked to care, retained in care, offered antiretroviral treatment and then supported in their treatment regimen to achieve improved health and viral suppression—making an individual living with HIV dramatically less infectious to others.

Research clearly shows that averting a single HIV infection saves $221,365 in lifetime health care costs[i], and getting people on anti-HIV treatment early lowers levels of HIV circulating in the body and reduces potential transmissions[ii]—saving lives and money in the long term—but we must invest now in care and treatment to reap those rewards. Caring for individuals early in their disease will increase the cost of care by $2.7 billion over five years and the majority of those costs will fall to federal discretionary programs like the Ryan White Program and will not be offset by entitlement programs.[iii]

Community-based providers are stretched to provide high-quality care with the scarce resources available. CAEAR Coalition is concerned that many HIV expert medical staff are scheduled to retire and the persistent financial pressures may accelerate the loss of trained professionals in the field. This additional pressure on an already overburdened system will leave many of the more than 200,000 HIV-infected individuals who do not know their HIV status without access to the care they need.

State budget cuts to health services create a continuing and growing challenge for ADAPs especially in states that are not expanding their Medicaid programs and the cost of medications continue to increase. In states that are implementing ACA through state marketplaces or the federal exchange, the need for insurance premium and co-insurance support is important to real access and affordability. 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 444 community health centers and outpatient clinics has consistently increased over the last five years and will rise significantly as ACA implementation is fully realized. Part C-funded federally qualified health centers, with access to HIV care and treatment expertise, will play an increasing role in providing HIV health care for individuals coming into to the health care system through ACA. Over 255,000 unduplicated persons living with HIV/AIDS receive medical care in Part C-funded community health centers and clinics each year. These faith- and community-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 decision of the U.S. Preventive Services Task Force to give an A grade to routine HIV testing combined with earlier guidance from the CDC, which recommended routine HIV testing for individuals 15-65, has had the intended impact and identified thousands of new clients for Part C-funded health centers and clinics. Additional service funding and training support will be required to serve these additional clients. CAEAR Coalition is encouraged by the partnership between the Bureau of Primary Care and the HIV/AIDS Bureau at the Health Resources and Services Administration to effectively address this new influx of clients and to enhance the provision of high-quality health care services and treatment access for people with HIV/AIDS.

Ryan White-Funded Programs are Economic Engines in their Communities
Ryan White-funded programs, including many community health centers, are small businesses providing jobs, vendor contracts and other types of economic development to low-income, urban and rural communities, frequently serving as anchors for existing and new businesses and investments. These organizations employ people in their communities, providing entry-level jobs, community-based training and career building.

For example, a large, urban community health center brings an estimated economic impact of $21.6 million, employing 281 people, and a small, rural health center has an estimated economic impact of $3.9 million, employing 52 people. Investing in AIDS care and treatment is an investment in jobs in communities that need it most.

Ryan White Program Key to Meeting the Goals of the National HIV/AIDS Strategy
CAEAR Coalition is eager to work with Congress to meet the challenges posed by the HIV/AIDS epidemic. In 2014, we have the collective chance to implement the community-embraced health care goals and policies in the National HIV/AIDS Strategy (NHAS). The National Strategy is an opportunity to reinvigorate the nation's response to the HIV/AIDS epidemic and stop its relentless movement into our communities. The Ryan White HIV/AIDS Program is key to reaching the NHAS goals of reducing new HIV infections, increasing access to care and improving health outcomes for people living with HIV/AIDS, and reducing HIV-related health disparities. Ryan White provides HIV/AIDS care and treatment services to a significantly

higher proportion of racial/ethnic minorities and women than their representation among reported AIDS cases—suggesting the programs and resources are targeted to underserved and marginalized populations. Early care and treatment are more critical than ever because we can help those infected learn their status and get them into care and treatment in order to improve their own health and the health of their communities.

The Ryan White Program's history of accomplishments for public health and people living with HIV/AIDS is a wonderful legacy for the U.S. Congress. There continues to be a vast need for additional resources to address the health care and treatment needs of people living with HIV across the country. In recognition of its high level of effectiveness and validation over time from credible federal government institutions, CAEAR Coalition urges the committee to provide the Ryan White HIV/AIDS Program with the funding levels authorized by Congress for Fiscal Year 2015.

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Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies March 28, 2014

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The American Association of Colleges of Pharmacy (AACP) is pleased to submit this statement for the record regarding FY2015 funding. The 130 accredited pharmacy schools are engaged in a wide range of programs funded by the agencies of the Department of Health and Human Services (HHS) and the Department of Education. Recognizing the difficult task of balancing needs and expectations with fiscal responsibility, AACP respectfully offers the following recommendations for your consideration as you undertake your deliberations.

US DEPARTMENT OF HEALTH AND HUMAN SERVICES - Health Resources and Services Administration (HRSA) AACP supports the Friends of HRSA recommendation of $7.5 billion for HRSA in FY15. Faculty at schools of pharmacy are integral to the success of many HRSA programs conducting research on rural health delivery via telemedicine. Dr. Anthony Rowe, from the University of Tennessee, received $1, 080,000 for "Integration of clinical simulation, distance education and delivery of care using telehealth, into interprofessional education. Schools of pharmacy are supported by HRSA to operate nine of the 57 **Poison Control Centers.** AACP supports the **Bureau of Health Professions** and the **National Center for Health Workforce Analysis.** Through the Pharmacy Workforce Center, AACP joins HRSA-funded efforts to compile national health workforce statistics to better inform future health professions workforce needs in the United States. **AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of $520 million for Title VII and VIII programs in FY15.** AACP member institutions are active participants in BHPr programs. Schools of pharmacy participate in Title VII programs, including Geriatric Education Centers and Area Health Education Centers (AHEC). These community-based, interprofessional programs are **essential** for supporting innovative educational

models addressing national issues at the local level through team-based, patient-centered care. They serve as valuable experiential education sites for student pharmacists and other health professions students. Dr. Patricia Darbishire, at Purdue University, received $268,000 for a comprehensive geriatric education progam. Pharmacy schools are eligible to participate in the **Centers of Excellence** program and the **Scholarships for Disadvantaged Students** program, to increase the number of underserved individuals attending health professions schools and increase minority health workforce representation. **Agency for Healthcare Research and Quality (AHRQ) - AACP supports the Friends of AHRQ recommendation of $375 million base funding for AHRQ programs in FY15.** Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). Dr. Rajender Aparasu, at the University of Houston, received $872,000 to study the "Anitcholinergics and Cognitive Decline in the Elderly with Depression." **Centers for Disease Control and Prevention (CDC) - AACP supports the CDC Coalition recommendation of $7.8 billion for CDC core programs in FY15 and the Friends of NCHS recommendation of $182 million for the National Center for Health Statistics.** Information from the NCHS is essential for faculty engaged in health services research and for the professional education of the pharmacist. The educational outcomes for pharmacy graduates include those related to public health. The opportunity for pharmacists to identify potential public health threats through regular interaction with patients provides public health agencies with on-the-ground epidemiologists providing risk identification measures when patients seek medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research and activities including delivery of immunizations, integration of pharmacogenetics in the pharmacy curriculum, inclusion of pharmacists in emergency preparedness, and the Million Hearts campaign. Dr. Randle Galluci, at the University of Oklahoma, received $1,938,000 from CDC and the NIOSH for "The role of IL-6 receptor in irritant dermatitis. **National Institutes of Health - AACP supports the Adhoc Group for Medical Research recommendation of at least $32 billion for NIH funding in FY15.** Pharmacy faculty are

supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the full spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In 2012, pharmacy faculty researchers received nearly $330 million in grant support from the NIH. Academic pharmacy sustains a strong commitment to increasing the number of biomedical researchers. Dr. Houjian Cai, at the University of Georgia, received $309,000 for study how to inhibit prostate tumors. Dr. Edith Nutescu, at the University of Illinois Chicago, received $526,000 for her study, "Patient-centered anticoagulation self-monitoring in minority patients."

US DEPARTMENT OF EDUCATION - The Department of Education supports the education of healthcare professionals by assuring access to education through student financial aid programs, educational research allows faculty to determine improvements in educational approaches; and the oversight of higher education through the approval of accrediting agencies. **AACP supports the Student Aid Alliance's recommendations to maintain the discretionary contribution to the $4860 maximum Pell grant.** Admission to a pharmacy professional degree program requires at least two years of undergraduate preparation. Student financial assistance programs are essential to assuring student have access to undergraduate, professional and graduate degree programs. **AACP recommends a funding level of at least $100 million for the Fund for the Improvement of Post Secondary Education** (FIPSE) as this is the only federal program that supports the development and evaluation of higher education programs that can lead to improvements in higher education quality.

Written Testimony

FY15 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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March 28, 2014

Mr. Chairman, Ranking Member, 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 consortium 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 FY2015 funding under section 301 and Title IV of the Public Health Service Act for the **National Institute of Dental and Craniofacial Research (NIDCR)** to be appropriated at a recommended level of 1.33% of the National Institutes of Health's (NIH's) total FY2015 funding level.

The FY2014 level enacted by the omnibus bill is $398.65 million for NIDCR. After transfers, NIDCR's total amount for obligation in FY2014 is $397.10 million. President Barack Obama's FY2015 budget proposal for NIDCR, $397.13, is at best stagnate if compared to total obligations, and at worse, a decrease of $1,519,000 if compared to the level Congress appropriated in the FY2014 omnibus bill. The end result is ongoing diminished grant opportunities that will only discourage young and talented researchers. Also, stagnate funding means NIDCR will not be able to keep up with the increasing rate of medical inflation.

Background

From 1998 to 2011, NIDCR's percentage of total NIH funding decreased from 1.53% to 1.33%, its lowest percentage, *amid a period when NIH's budget doubled.* Save for a slight bump in 2012, this percentage remains at 1.33%. The Friends of NIDCR has been working to reverse this troublesome trend—and return NIDCR research to a percentage of total NIH funding that is more appropriate and proper. For FY2014, NIDCR's percentage of total NIH funding is 1.33%.

- If Congress enacts the president's FY2015 budget figures for NIH and NIDCR, then NIDCR's percentage of total NIH funding would be at an all-time low, 1.31%.

The Friends of NIDCR would welcome the opportunity to work with members of this Subcommittee to ensure NIDCR funding realizes a percentage of total NIH funding that is appropriate, yet realistic. The research performed by NIDCR justifies this approach. This is why the Friends of NIDCR recommends a modest increase in NIDCR's percentage of total NIH funding for FY2015 of 1.33% based upon the president's FY2015 budget request. This is also a consistent recommendation based upon the level enacted by Congress for FY2014.

NIDCR: A Renown Leader in Research

For 66 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 for health to the public, health professionals, researchers, and policy-makers.

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 All Americans

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: 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 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). HPV is now the cause of more oral cancers than smoking. NIDCR supports research aimed to gain a clearer take on HPV-related oral cancers, including their incidence, risk factors, natural history and biology.

Craniofacial Biology. Scientists are defining the genetics that underlie the formation of the head and skull, and researchers are identifying the key areas for craniofacial malformations. For example, NIDCR-supported research has detected proteins associated with craniosynostosis, which is the premature fusion of a baby's skull bones that causes asymmetric skull growth. NIDCR believes this research could provide the foundation for the development of early detection methods and more effective treatments.

Genome-wide Association Studies. NIDCR supports the first genome-wide association studies ("GWAS") of cleft lip and/or palate and dental caries. The studies offer significant potential for understanding the molecular and genetic basis of cleft lip and/or 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. The dental caries GWAS revealed areas of the genome that make an individual more likely to develop decay. Moreover, NIDCR researchers have identified six areas of the genome that may put a person at risk for moderate or severe periodontal disease and patients afflicted with Sjögren's Syndrome and TMJD can benefit from this program.

Moreover, NIDCR research benefits millions of Americans with:

- Periodontal Disease,
- Chronic Dry Mouth,
- Chronic Facial and Oral Pain, such as TMJD, and
- Bone and Cartilage Regeneration.

How NIDCR Research Makes a Difference

Because Friends of NIDCR is a broad-based coalition of members, we are able to share first-hand perspectives from across the spectrum of the oral health community.

The TMJ Association:
During the past decade, NIDCR-funded research directed toward Temporomandibular Disorders has been a "game changer." Previously thought to be a condition about teeth and jaws, research has demonstrated that this is a complex condition mediated by genes, sex, age, and epigenetics. We now also know that for many, TMD is a chronic pain condition and that in addition these patients also present with other comorbid pain conditions that co-occur more than by chance. These findings have truly revolutionized the way that these conditions are researched and will ultimately be treated. It is important to note that the National Institutes of Health are the only sources of funding of TM Disorders in the United States. We rely on their resources to improve the health care and quality of life for the 35 million TMJ patients in this country. Our hope is in science and the NIH, through its Institutes such as NIDCR, provides us with that hope.

The American Chronic Pain Association:

For many decades, pain has not been recognized as a clinical issue in its own right; if has been seen as a symptom or side effect of other diagnoses. But pain has a huge medical, economic, and social impact. It can delay healing, drive up the cost of care, lead to loss of productivity and disability, and erode quality of life for those afflicted. The NIDCR has led the way in treating pain as a condition worthy of attention. NIDCR research has been forward-looking and comprehensive in its understanding of pain and has offered hope to millions who so often find their concerns overlooked in the scientific community. We urge you to fully fund the NIDCR so that its significant work can continue.

Ostrow School of Dentistry of the University of Southern California:
NIDCR funding is essential to the success of several areas of research at USC that directly impact millions of people in the US and worldwide. First, thanks to the NIDCR, we have made progress in understanding cleft lip and palate, craniosynostosis, and other birth defects of the craniofacial region. According to the CDC, the lifetime cost of treating the children born each year in the US with cleft lip or palate is $697 million. Every day, our researchers come closer to better treatments and preventive measures to help reduce this cost and improve quality of life. Moreover, we are working to leverage the dramatic potential of stem cells to regenerate bone and other tissues that may be lost due to birth defects, trauma, or disease. The NIDCR also funds our efforts to prevent dental caries, which is a major global health concern affecting 92% of American adults. Finally, the NIDCR supports our community outreach program in California's diverse population, through which we are investigating how to improve oral health for everyone in America.

New York University College of Dentistry:
Research and scholarship are integral components of the New York University College of Dentistry (NYUCD). A priority for NYUCD is to educate men and women of science, by which we mean sophisticated consumers of research. We believe that while every graduate does not have to become a scientist, in the sense of becoming a producer of new knowledge, a learned profession does require that every graduate be able to think for herself or himself, be an intelligent user of research, able to critique it, and comfortable with the structure and syntax of modern biomedical science. Only through this process can graduates immunize themselves against fads, junk science, unsubstantiated conjecture, and the pervasive, self-declared, self-normed claim of excellence so characteristic of our time. To achieve this goal, NYUCD is committed to continually strengthening our research program. Over the past decade, NYUCD has consistently ranked in the top 10 schools to receive NIDCR funding. These grants have enabled NYUCD to develop robust research programs in the areas of infectious disease, including caries, periodontal disease, microbiome and HIV studies, cancer, pain, craniofacial development, bone biology, biomaterials, and tissue engineering. Because NYUCD graduates come from virtually every state in the nation, because NYUCD graduates more than eight percent of U.S. dentists annually, and because the majority of NYU dental graduates return to their home states to practice, the impact of NIDCR funding is amplified, thus enabling NYUCD to make a tangible impact on the health not just of New Yorkers, but of society at large.

Research Drives the Economy, Innovates

Despite the fact 54% of Americans thought federal spending for medical and health research should be exempt from across-the-board cuts outlined in the Budget Control Act of 2011[1], the ramifications of sequestration still linger. However, Friends of NIDCR maintains that investment in

[1] "More than Half of Americans Doubt U.S. Global Leadership in 2020," Research!America press release, March 14, 2012, http://www.researchamerica.org/release_14march12_poll

medical research powers our innovation economy and provides life-saving treatments and cures. For example, a typical NIH grant supports the salaries of about seven high-tech jobs. Moreover, cuts or stagnate funding will only set the U.S. back at a time when other countries are rapidly increasing investment in research. Eighty-five percent of likely voters are concerned about the impact of a decreased federal investment in research, including the possibility of scientists leaving their profession or moving abroad to countries with a stronger investment in research.[2] NIDCR-funded grants contribute to our nation's economy and keep scientists from looking abroad for work. FY2013 NIDCR-funded grants had a presence in 120 congressional districts (often multiple awards for a congressional district) in 43 states and territories. This equates to 75 percent of NIDCR-funded research being distributed to grantees at universities, dental schools, and medical schools, primarily in the U.S. Therefore, a significant portion of NIDCR-funded research occurs away from the NIH campus. However, this nationwide NIDCR presence will surely decline with decreased investment in research.

Health Disparities Research Program

Finally, through the NIDCR Health Disparities Research Program, 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. As a result of the program, tailored interventions to prevent dental caries and oral cancer are being tested in community settings such as urban public housing, community health centers, rural Project Head Start centers, low-income senior housing facilities, and primary medical care offices.

RECOMMENDATION

Eighty-five percent of Americans are concerned about stagnate funding for medical research.[3] Proper funding of medical and health research 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 early stages of oral cancer—or searching for breakthroughs to help combat facial and oral pain—we all benefit when we make NIDCR 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 to fund NIDCR at 1.33% of NIH's funding level, so that it can realize the full potential of its worthy mission and sustain its beneficial scientific research.**

Thank you for the opportunity to present our written testimony before the Subcommittee.

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[2] Ibid.

[3] "America Speaks," Poll Data Summary Volume 13, Research!America, http://www.researchamerica.org/uploads/AmericaSpeaksV13.pdf

NATIONAL INDIAN EDUCATION ASSOCIATION

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

Testimony on FY 2015 Departments of Education and
Health and Human Services Programmatic Budgets

March 28, 2014

The National Indian Education Association (NIEA) is the most representative and inclusive Native education organization in the United States. NIEA's principal goal is to advance comprehensive and equal educational opportunities for American Indian, Alaska Native, and Native Hawaiian students. To fulfill this vision, NIEA supports sovereignty over education, traditional Native cultures, and values that enable Native learners to become contributing members of their communities.

Through treaties, federal law, and U.S. Supreme Court decisions, the federal government has a fiduciary trust obligation to provide parity in access and equal resources to Native education. National fiscal and policy concerns should not be addressed by decreasing funds and investment to Native students or the programs that serve them. Rather, Native education, including those programs and services under the Departments of Education (ED) and Health and Human Services (HHS), is one of the most effective and efficient investments the federal government can make.

As tribes and Native communities work with Congress for parity in access to increase their role and responsibility in administering education, federal support for tribal governments and Native education institutions has continued to shrink as a percentage of the federal budget. Historical funding trends illustrate that the federal government is abandoning its trust responsibility by decreasing federal funds to Native-serving programs by more than half in the last 30 years. Sequestration only exacerbated those shortfalls.

While FY 2014 funding increases over sequestration levels were welcome, several Native-serving programs remained flat with 2013 sequestration levels, such as Elementary and Secondary Education Act Title VII funding. These levels continue to be insufficient for effectively and equally serving Native students. Partly as a result of this insufficient funding, Native students continue to lag behind their non-Native peers. Graduation rates often hover around 50 percent in many states, which can lead to increased substance abuse, criminal acts, and extended periods of unemployment. If the 25,000 Native students who dropped out of the Class of 2010 had graduated, an additional $295 million would likely have been added to total annual earnings, supplementing local and regional economies.

To provide tribes and Native communities the educational institutions that supplement economic growth, the federal government should fund Native education programs at the levels requested below as they detail the minimum appropriations needed to maintain a system that is already struggling and underfunded. The following funding requests illustrate continuing need for Native programs but do not comprise the full list of budget requests, which can be found in the FY 2015 NIEA Budget Document. Further, NIEA supports the budget requests of the National Congress of American Indians and American Indian Higher Education Consortium.

State-Tribal Education Partnership (STEP) Program (ED)

- **Provide $5 million.** *An increase of $3 million.*

Congress appropriated roughly $2 million dollars for the STEP program to five participating tribes under the Tribal Education Department appropriations. In order for this program to successfully achieve the original intent of the appropriation, it must receive its own line and authorization of appropriations in FY 2015. Collaboration between tribal education agencies and state education agencies is crucial to developing the tribal capacity to assume the roles, responsibilities, and accountability of tribal education departments that increase self-governance in Native education.

Impact Aid (ED)

- **Provide $2 billion for Impact Aid, under ESEA Title VIII.** *An increase of $711 million.*

Impact Aid provides direct payments to public school districts as reimbursement for the loss of traditional property taxes due to a federal presence or activity, including the existence of an Indian reservation. With nearly 93 percent of Native students enrolled in public schools, Native students were disproportionately affected by the devastating reductions implemented under sequestration. Additional funds are required to cover previous Impact Aid shortfalls.

Title VII (Indian Education Formula Grants in ED)

- **Provide $198 million under ESEA Title VII, Part A.** *An increase of $74 million.*

This grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards as their non-Native peers. Title VII funding, which was mainatined at 2013 sequestration levels in FY 2014, only reaches 500,000 Native students leaving over 100,000 without supplementary

academic and cultural programs in their schools. As Native students continually lag behind their non-Native peers in educational achievement, increased funding is necessary to address this substantial gap.

Native Hawaiian Education Program (ED)

- **Provide $35 million under ESEA Title VII, Part B.** *An increase of $3 million.*

The Native Hawaiian Education program empowers innovative culturally-appropriate programs to enhance the quality of education for Native Hawaiians. When establishing the Native Hawaiian Education Program, Congress acknowledged the trust relationship between the Native Hawaiian people and the United States. These programs strengthen Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes.

Alaska Native Education Equity Assistance Program (ED)

- **Provide $35 million under ESEA Title VII, Part C.** *An increase of $5 million.*

This assistance program funds the development of curricula and education programs that address the unique educational needs of Alaska Native students as well as the development and operation of student enrichment programs in science and mathematics. Other eligible activities include professional development for educators, activities carried out through Even Start and Head Start programs, family literacy services, and dropout prevention programs.

Vocational Rehabilitation Services Projects for American Indians with Disabilities (ED)

- **Provide $67 million to Vocational Rehabilitation Services Projects.** *Create a line item of $5 million for providing outreach to tribal recipients.*

According to the Centers for Disease Control and Prevention, approximately 30 percent of Native adults have a disability—the highest rate of any other population in the nation. Of those, 51 percent reported having fair or poor health. A number of issues contribute to this troubling reality, including high incidences of diabetes, heart disease, and preventable accidents. As a result, tribes have an extraordinary need to support their disabled citizens in improving their health, attaining experiential learning courses, and becoming self-sufficient. Tribes have limited access to funding for vocational rehabilitation and job training as compared to states and $67 million would begin to put tribes on par to support their disabled citizens.

Native Languages Preservation (Esther Martinez Program Grants in HHS)

- **Provide $12 million for Native language preservation with $5 million designated to fund the Esther Martinez Native Language Programs.** *An increase of $3 million.*

Native language grant programs are essential to revitalizing Native languages and cultures, many of which are at risk of disappearing in the upcoming decades. In addition to protecting Native languages, these immersion programs promote higher academic success for participating students in comparison to their Native peers who do not participate. The federal budget should include $12 million for Native language preservation activities which would include $5 million designated to support Esther Martinez Native Language Programs' immersion initiatives.

Conclusion

Thank you for your consideration of this testimony. For more information or to attain NIEA's complete budget document with all FY 2015 requests for the Departments of Education and Health and Human Services, please contact Ahniwake Rose, NIEA Executive Director, at *arose@niea.org*.

Monika Johnson-Hostler
Board President
National Alliance to End Sexual Violence

Testimony Presented For the Record

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

March 28, 2014

On behalf of the National Alliance to End Sexual Violence (NAESV) representing 56 state and territorial sexual assault coalitions and more than 1300 local rape crisis centers, I am respectfully requesting FY 2015 federal funding to support comprehensive rape prevention and education and direct services for victims of sexual violence. Specifically, NAESV is requesting $50.6 million, $45 million for the program and $5.6 million in PHS evaluation tap funds, for the Rape Prevention & Education Program (RPE) in the Centers for Disease Control and Prevention's (CDC) National Center for Injury Prevention and Control budget. In addition, NAESV is requesting level funding of $160 million for the Preventive Health and Health Services Block Grant, which includes a $7 million set-aside for rape prevention services, in CDC's National Center for Chronic Disease Prevention and Health Promotion budget. Together, we must make our communities safer.

One in five women has been the victim of rape or attempted rape. Nearly one in two women has experienced some form of sexual violence and one in five men has experienced a form of sexual violence other than rape in their lifetime. The CDC National Intimate Partner and Sexual Violence Survey study confirmed that the impacts of sexual violence on society are enormous.

Over 80% of women who were victimized experienced significant short and long-term impacts related to the violence such as Post-Traumatic Stress Disorder (PTSD), injury (42%) and missed time at work or school (28%). The CDC report also shows that most rape and partner violence is experienced before the age of 24, highlighting the importance of preventing this violence before it occurs.

The 2013 Rape Crisis Center Survey, distributed by NAESV, demonstrated that over 75% of these programs lost funding in the last year, causing programs to have to reduce services, lay off staff or even close. Over one third of rape crisis centers reported having a waiting list for services, with victims waiting most often for counseling services and support groups. Three out of four programs cannot meet current requests for community prevention programs. As you begin the FY 2015 appropriations process, please fund the following priorities.

Rape Prevention and Education (RPE) – The National Alliance to End Sexual Violence urges Congress to provide $45 million for the program and an additional $5.6 million in PHS evaluation tap funds for RPE program evaluation, with the goal of creating a more extensive evidence base for sexual violence prevention. Funding for RPE through CDC's Injury Center provides formula funding to every state and territory to raise awareness of the problem of sexual assault, support efforts to prevent first-time perpetration and victimization, and bring together diverse partners to develop, implement and evaluate statewide sexual assault prevention plans. The RPE program engages boys and men as partners, supports interdisciplinary research collaborations, fosters cross-cultural approaches to prevention, promotes healthy relationships, and funds the critically important National Sexual Violence Resource Center. High profile

cases have increased the demand for prevention and education beyond the current capacity of state sexual assault coalitions and local rape crisis centers. The expansive media attention also points to the need for comprehensive community responses to sexual violence like those funded by RPE. With FY 2013 funding, the program educated more than 1.8 million students, answered 340,000 hotline calls, and conducted over 105,000 trainings nationwide.

Formula Shortfall - Beginning in FY 2014, a new RPE funding formula is being implemented based on VAWA 2013. While the formula provides a base funding of $150,000 for all 50 states, Washington, DC and Puerto Rico, and $50,000 for territories, it reduces the funding provided to large states. In addition, CDC is altering the fiscal year of the program which results in reduced funding stretched over a span of 15 months, further penalizing state coalitions and local rape crisis centers at the same time demand for rape prevention and education is increasing due to high profile cases causing alarm in local communities. Increased funding is required to avoid critical shortfalls.

Program Evaluation - There is a need to increase the evidence base for sexual violence prevention. However, those efforts should be funded by additional funding – not from program funds to states and local rape crisis centers. Most recently, CDC decided to make "state level evaluation" mandatory despite many states starting local, regional or targeted evaluation efforts. It is the CDC's stated perspective that this would be "less labor intensive." However, this strategy forces everyone down one path, without a recognition of the work and progress that is currently underway in many states, nor of each state's individual goals, projects or bandwidth to accomplish the work. To date, CDC has not demonstrated that they have developed any

significant sexual violence specific research and evaluation over the years. Rather, all indicators suggest that they are relying on proxy measures that have been developed for other issues such as alcohol use, which are not suited to measure sexual violence. We support the CDC proposal to use PHS evaluation tap funding for this purpose. We do not want program funds diverted from the communities at a time when demand for prevention and education, as well as services, is increasing at such a rapid rate.

Preventive Health & Health Services Block Grant (PHHSBG) – We are very grateful for the FY 2014 funding of $160 million enacted by Congress and disappointed with the Administration's efforts to eliminate the program which provides much needed resources to communities. The Public Health Service Act of 2010 authorizes the block grant (CDC, Chronic Disease) and provides a rape set-aside provision which guarantees at least $7 million for rape services and prevention. Please retain the block grant funding that supports local rape crisis centers providing services, statewide training and technical assistance to increase capacity to assist rape victims and prevent future victimization. Maximum funding is requested.

We must have the resources to meet the education and prevention needs in the community. Victims deserve support, our young people deserve to grow up safely, and research tells us that appropriate and early intervention and prevention can mitigate the costs and consequences of sexual violence and prevent that violence from occurring in the first place. The best way to prevent victimization is to prevent first time perpetration. The best way to convict a rapist is to support and advocate for the victim, obtain evidence and provide assistance and training to law enforcement.

Thank you for the opportunity for the National Alliance to End Sexual Violence to present testimony for the record as the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies begins the process to prepare the FY 2015 Appropriations Bill. If you need further information, I can be reached at 919-871-1015, monika@nccasa.org and www.endsexualviolence.org.

Statement of Michael Riksen
Vice President – Policy & Representation
National Public Radio
Before the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, U.S. House Committee on Appropriations

March 28, 2014

Dear Chairman Kingston, Ranking Member DeLauro and Members of the Subcommittee,

Thank you for this opportunity to urge the Subcommittee's support for an annual federal investment of $445 million in public broadcasting through the Corporation for Public Broadcasting (CPB). With your support, the public radio system, consisting of some 950 locally managed, locally controlled and locally programmed stations, serve communities all across America. And these stations are as diverse as the communities they represent. Public radio is committed to being America's public radio, bringing the diverse and changing voices of Americans to the airwaves. We strive to create a more informed public, one challenged and invigorated by a deeper understanding and appreciation of events, ideas, and culture within the United States and across the globe.

The public radio system, a uniquely American public service, non-commercial, media enterprise, includes stations in every state capitol and hundreds of American communities, large and small, urban and rural. Producers and distributors of public radio programming, including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX) and NPR are united by a commitment to the highest standards of journalist ethics. Every minute of every program broadcast to some 38 million Americans weekly is routed through the Public Radio Satellite System (PRSS), a distribution utility owned by the public radio system.

Partnerships and collaborations are integral components of the programming and service found in the public radio system. Available on air, online, and on new and emerging mobile platforms, public radio is expanding its ability to reach audiences. And as traditional media undergoes dramatic changes, public radio is positioning itself to serve the needs of a growing audience in a shifting media landscape and rapidly changing world.

A clear example of these new adaptations to improve journalism and meet audience needs comes from the recently formed merger between St. Louis Public Radio and the St. Louis Beacon newspaper, the area's two largest nonprofit news organizations. This move combines newsrooms and significantly changes the face of independent local news in the region by providing more depth and perspective on issues and stories that impact the community. The consolidation creates an innovative model for a multiplatform news operation that results in more in-depth coverage of urban events and issues. St. Louis Public Radio's move to join forces and expand serves as an example of how public radio news organizations are adjusting to an ever-changing media environment that involves greater competition for consumers and financial support.

This new merger is just one among a growing list of public broadcasters teaming up with other nonprofit news outlets to beef up their local and investigative journalism. In Denver, Rocky Mountain PBS, public radio station KUVO, and I-News, the Rocky Mountain Investigative News Network, merged to create a cross-platform news operation that could better cover Colorado. WWNO in New Orleans hired its first-ever news director last spring to expand its coverage of stories. Oregon Public Broadcasting is building a statewide news network with 40 to 50 small news outlets across Oregon. Lastly, Harvest Public Media, a reporting collaboration of public radio stations KCUR, KBIA, Iowa Public Radio, Nebraska Public Broadcasting, KUNC and WUIS, focuses on issues of food, fuel and field. Based at KCUR in Kansas City, Harvest covers these agriculture-related topics through an expanding network of reporters and partner stations throughout the Midwest.

But the partnerships don't stop there for public radio. A recent collaboration includes Boston's WBUR and NPR joining forces to expand and re-launch the daily public radio show *Here & Now* as a two-hour national news program for audiences in the middle of the day. The program airs weekday afternoons and is aggressively updated to provide local audiences with live, updated news coverage during mid-day.

Public radio's partnerships with public safety officials play a critically important role when natural or man-made disasters strike. Public radio stations provide essential and timely public emergency information, such as evacuation routes, shelter locations and severe weather updates. Effective emergency warnings allow people to take actions that save lives, and reduce damage and human suffering. Federal funding helps to bring crucial news and alerts to millions of Americans.

Public radio's innovative partnerships also expand our public service mission by enabling radio reception to all Americans during local emergency situations. This year, 26 public radio stations based in Alabama, Florida, Louisiana, Mississippi and Texas are working with NPR Labs, the Public Radio Satellite System (PRSS) and the U.S. Department of Homeland Security/FEMA to demonstrate the delivery of emergency alerts to people who are deaf or hard-of-hearing. This is the first effort to deliver real-time accessibility-targeted emergency messages, such as weather alerts, via radio broadcast texts. Our hope is to expand the pilot over time to other regions of our country thru the use of radio equipment to reach people who are both deaf and blind and non-English speaking.

In addition, many public radio stations provide critical services through partnerships with radio reading services. These long established centers are in every major market in the United States to provide millions of visually impaired persons the ability to function more independently in their communities.

Music in America would sound very different without public radio. Local stations take creative risks, nurture new talent, and give emerging artists a chance to be heard. They celebrate traditional music genres like classical and jazz, and partner with local music organizations to take these art forms to new heights of performance excellence and new audiences. And they play a key role in their local music economics, sustaining and growing the careers of musicians by connecting them to local listeners. Across the country, more than 180 local public radio stations

have full-time music formats and more than 650 stations air play music as part of their programming lineups.

Mr. Chairman and Ranking Member DeLauro, public radio is essential in providing news, information and cultural programming to America and connecting with audiences wherever they are. We're embracing America's changing demographics and using digital media to connect better, more quickly and in more diverse ways. Today's public radio isn't going away, it's going everywhere and we are working every day to earn the trust of the 38 million Americans who rely on us for news and insights that guide and inform. We ask for your continuing support in funding for stations that serve your communities, your constituents and America's Democracy.

Robert J. Beall, Ph.D.
President and Chief Executive Officer
Cystic Fibrosis Foundation

On behalf of the Cystic Fibrosis Foundation (CFF) and the 30,000 people with cystic fibrosis (CF) in the United States, we submit the following testimony to the House Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on our funding requests for fiscal year 2015. The Foundation requests the highest possible funding level for the National Institutes of Health (NIH), particularly the National Center for Advancing Translational Sciences (NCATS) and programs under its jurisdiction, including the Cures Acceleration Network (CAN) and the Clinical and Translational Science Awards (CTSA).

Collaboration and Innovation: The Future of Drug Development

In previous public forums, Chairman Kingston has expressed his view that NIH must use its taxpayer-funded resources wisely. As is demonstrated in the testimony below, NIH does use appropriated funds effectively by supporting programs that promote efficiency and innovation in drug discovery and encouraging collaboration across sectors. Many of these effective, collaborative ventures aim to translate basic research into promising potential treatments, speeding the discovery of therapies for those with serious illnesses like cystic fibrosis. We urge you to ensure that these critical programs are sufficiently funded and receive the support they need. For those with rare genetic diseases like CF, treatments and cures cannot wait.

As an example of the NIH's cooperative, innovative approach, in February the agency announced the establishment of the Accelerating Medicines Partnership (AMP), a joint venture

between NIH, pharmaceutical companies, and several non-profit organizations to characterize biomarkers and distinguish biological targets that are most likely to respond to new therapies. The AMP will begin with three to five year pilot projects in Alzheimer's disease, type 2 diabetes, rheumatoid arthritis and systemic lupus erythematosus.

Through this cross-sector partnership, NIH and industry partners share expertise, resources, and data in order to speed the development of treatments. Furthermore, industry partners have agreed to make AMP data and analyses available to the biomedical community for use in future study.

Drug development is risky, expensive, and time-consuming, and there is a 95% failure rate for drug candidates. This kind of cross-sector partnership aims to reduce the time, cost, and risk of drug development by sharing resources so diseases can be analyzed in ways that drug companies have not been able to do on their own.

Importantly, industry will fund one-half of the $230 million budget while NIH will provide the other half. The federal money used for this project acts as seed money, a jumping off point for private sector investment in drug discovery for serious diseases. This type of cooperative approach saves taxpayer funds in the long run and can save lives.

While AMP is not administered by the National Center for Advancing Translational Sciences (NCATS), this NIH center spearheads similarly innovative programs that encourage collaboration, improve the process by which diagnostics and therapeutics are developed, and improve the efficiency of the translation of basic scientific discoveries into new therapies.

For example, the Cures Acceleration Network (CAN), a program under the umbrella of NCATS, funds a variety of initiatives designed to address scientific and technical challenges that hinder transitional research. For instance, CAN provides funding for the Tissue Chip for Drug

Screening Initiative, a joint project with the Defense Advanced Research Projects Agency (DARPA) and the Food and Drug Administration (FDA) to develop 3-D human tissue chips. These chips, composed of diverse human cells and tissues, mimic how drugs interact with the human body. If successful, these chips could make drug safety and efficacy assessments possible at an earlier stage in drug development, enabling investigators to concentrate on the most promising new drugs.

Unfortunately, CAN has been chronically underfunded. Since its inception as part of the Patient Protection and Affordable Care Act in 2010, it has been funded at approximately $10 million per year for fiscal years 2012, 2013, and 2014. We urge the Committee to provide at least the funding level requested in the President's fiscal year 2015 budget – $29.8 million. CAN needs additional funding for projects that will help move new treatments to patients.

Similarly, the Clinical and Translational Science Awards (CTSA) program in the NCATS Division of Clinical Innovation demonstrates NCATS' innovative, collaborative approach. This program supports a national consortium of more than 60 medical research institutions that work together on research. Its goals are to accelerate the process of translating laboratory discoveries into treatments for patients, train a new generation of researchers, and engage communities in clinical research efforts.

Institutional CTSA awards provide academic homes for translational sciences and support research resources needed by local and national research communities to improve the quality and efficiency of all phases of translational research. They also support the training of clinical and translational scientists and the development of all disciplines needed for a robust translational research workforce.

CTSA funds have the potential to be used in new ways. For example, CTSA's academic homes can serve as a platform for sharing patient registry data. As the CF Foundation has seen with its Therapeutics Development Network of clinical trial sites, the sharing of patient registry information, including demographics and health outcomes, among sites is integral to conducting CF research. This strategy could be beneficial in the wider disease community.

A Culture of Collaboration: The Cystic Fibrosis Model

The Cystic Fibrosis Foundation has long been engaged in partnerships with industry and supports a collaborative network of care centers and clinical trial sites. As such, CFF knows firsthand that this type of cooperation can lead to the targeted treatments that change the face of many life-threatening diseases.

Because drug research and development is a lengthy, expensive and risky process, CFF pioneered a successful "venture philanthropy" business model to drive drug development for this rare disease. By collaborating with pharmaceutical companies and providing financial, scientific, and clinical support in order to "de-risk" the development process, CFF speeds development of much-needed treatments.

Through its venture philanthropy model, the Foundation is able to invest in promising CF research and a robust pipeline of potential therapies that target the disease from every angle. Nearly every CF drug available today was made possible because of the Foundation's support and ongoing work with researchers and the pharmaceutical industry to find a cure.

In January 2012, the Food and Drug Administration approved Kalydeco, a groundbreaking cystic fibrosis drug developed by Vertex Pharmaceuticals in partnership with the CF Foundation. This targeted drug is the first to address the underlying genetic cause of cystic fibrosis in a subset of the CF population.

Kalydeco was approved in only 3 months, one of the fastest approvals in the FDA's history. According to Margaret A. Hamburg, M.D., Commissioner of the FDA, "The unique and mutually beneficial partnership that led to the approval of Kalydeco serves as a great model for what companies and patient groups can achieve if they collaborate on drug development."

Throughout Kalydeco's review, the Cystic Fibrosis Foundation and renowned CF experts worked closely with Vertex Pharmaceuticals and the FDA, providing valuable insight on specific issues related to CF, clinical research on CF treatments, and other issues related to the product and its review. We believe that this collaborative process contributed to a more efficient evaluation, and is a testament to what can be achieved when stakeholders collaborate across sectors on critical drugs for patients.

Akin to AMP, the Cystic Fibrosis Foundation also recognizes the profound importance of data sharing, which is a critical way to enable efficient drug development. The Cystic Fibrosis Foundation Therapeutics Development Network (TDN) of clinical trial centers has accumulated data from over 40 cystic fibrosis (CF) studies in the last 15 years. This data resides in a repository specifically meant to facilitate sharing among our research community.

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As the Committee determines its funding levels for fiscal year 2015, we request your attention to the critical nature of NIH's work and the innovation it supports, and urge robust funding for this important agency. The CF Foundation stands ready to work with the Committee, NIH, and Congressional leaders on the challenges ahead. Thank you for your consideration.

Testimony of
Don Wildman, Host, Travel Channel's *Mysteries at the Museum*
On behalf of the American Alliance of Museums (www.aam-us.org)
To the House Committee on Appropriations Subcommittee on
Labor, Health and Human Services, Education and Related Agencies
March 28, 2014

Chairman Kingston, Ranking Member DeLauro and members of the Subcommittee, my name is Don Wildman, and for six highly rated seasons, I've had the extreme honor of hosting a television show, *Mysteries at the Museum* (Thursday nights on the Travel Channel), which tells the stories behind artifacts in museum collections. My testimony today is presented on behalf of the American Alliance of Museums, the largest organization of museums and museum professionals in the world, and we are respectfully asking the Subcommittee to provide $38.6 million for the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), its fully-authorized amount, in fiscal year 2015.

Museums are among our nation's most popular, most trusted and most beloved institutions. There are approximately 850 million visits to American museums each year, more than the attendance for all major league sporting events and theme parks combined. Museums also spend over $2 billion on educational programming, and a total of $21 billion in their local economies. Clearly museums are economic engines and job creators.

IMLS is the primary federal agency that supports the museum field, and OMS awards grants to help museums digitize, enhance and preserve their collections; provide teacher training; and create innovative, cross-cultural and multi-disciplinary programs and exhibits for schools and the public.

It's no surprise that the appropriations bill that funds education supports this agency, because museums are indeed key education providers. They design exhibitions, educational programs, classroom kits, and online resources in coordination with state, local and common core curriculum standards in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography, and social studies. Museums also offer experiential learning opportunities, STEM education, mentoring, and job preparedness.

Whatever education looks like in the future, one component will certainly be the development of a core set of skills: critical thinking; the ability to synthesize information; and the ability to innovate, to be creative and to collaborate. Museums are uniquely situated to help learners develop these core skills.

In late 2010, legislation to reauthorize IMLS for five years was enacted (by voice vote in the House and by unanimous consent in the Senate). The bipartisan reauthorization included several provisions proposed by the museum field, including enhanced support for conservation and preservation, emergency preparedness and response and statewide capacity building. The reauthorization also specifically supports efforts at the state level to leverage museum resources, including statewide needs assessments and the development of state plans to improve and maximize museum services throughout the state. The bill (now Public Law 111-340) authorized $38.6 million for the IMLS Office of Museum Services to meet the growing demand for museum programs and services. The fiscal year 2014 appropriation of $30,131,000 represents a nearly 15% decrease from the fiscal year 2010 appropriation of $35,212,000.

Perhaps the best way to demonstrate the importance of the IMLS Office of Museum Services is to highlight just a few of the grants awarded in 2013 to museums in states represented by subcommittee members:

Minority Job Training— The National Underground Railroad Freedom Center (Cincinnati, OH) was awarded $150,000 to recruit talented graduates from colleges and universities across the country, with a focus on those from Historically Black Colleges and Universities. The graduates will serve as apprentices and receive on-the-job training and classroom instruction over two years so as to develop the expertise and skills needed to strengthen African American museums and institutions.

Environmental Science— The Calvert Marine Museum Society (Solomons, MD) was awarded $142,500 to develop and install an exhibit on the ecosystem of the Patuxent River and Chesapeake Bay. They are partnering with local schools and community groups to facilitate lifelong learning of scientific concepts and environmental stewardship.

Collections Care— The Birmingham Civil Rights Institute (Birmingham, AL) was awarded $74,277 to safeguard its collections to ensure that they will be available for use by current and future students, the general public, researchers and staff.

STEM Education— The University of Alabama/Alabama Museum of Natural History (Tuscaloosa, AL) was awarded $99,998 to create the Discovery Learning Lab to give middle and high school-aged students access to "geek" mentors who will guide them in explorations of digital technologies not readily available at home or school in low-income areas. This program exposes teens to STEM disciplines, skills, activities, and software at the lab and in a cyberspace environment.

Public Access— The Historic Hudson Valley (Pocantico Hills, NY) was awarded $149,837 to create an online database of its collections for the wider public to use.

Scientific Literacy—The Great Lakes Science Center (Cleveland, OH) was awarded $80,579 for an exhibit focusing on Northeast Ohio issues, as part of its Great Lakes Story gallery. The interactive exhibit will feature touch-screen monitors, game-format activities, interviews with experts and an interactive map to provide informal STEM education rooted in real-world scientific challenges relevant to the region.

Native American History— The Ohio Historical Society (Columbus, OH) was awarded $24,941 to implement The Oklahoma & Ohio Exchange, a collaborative project with the Eastern Shawnee Tribe of Oklahoma, Ohio K-12 teachers and Oklahoma K-12 teachers. The project focuses on the subject of "Indian Removal," a federal policy that relocated Native American tribes living east of the Mississippi River to lands west of the river, which left little historical record and makes teaching and learning about both Native American history and contemporary Native American life in Ohio difficult.

Mobile Science Classroom—The Discovery Center at Murfree Spring (Murfreesboro, TN) was awarded $103,849 to convert a school bus into a mobile science classroom for elementary school students.

Digitization— The Country Music Hall of Fame (Nashville, TN) was awarded $150,000 for a digitization initiative to preserve and increase access to the museum's unparalleled collection.

Collections Stewardship— The University Museum, University of Arkansas (Fayetteville, AR) was awarded $31,464 to improve its zoology collection and make it more accessible to researchers.

Endangered Species—Zoo Atlanta (Atlanta, GA) was awarded $486,580 to create a national program to aid in the diagnosis, treatment and prevention of disease in endangered species.

Traveling Exhibitions—Artspace (New Haven, CT) was awarded $99,225 to create a small self-contained gallery unit for traveling exhibitions. The museum will schedule six onsite and six travelling exhibitions, along with free artist and curator talks, demonstrations and workshops.

Science Literacy/College Preparedness—The Peabody Museum of Natural History (New Haven, CT) was awarded $149,585 to present a free after-school program focused on science literacy, college preparation and career awareness to a diverse group of high school students from the New Haven community who are traditionally underrepresented in the sciences.

Youth Literacy— The Connecticut Children's Museum (New Haven, CT) was awarded $149,475 to address youth literacy and disparities in access to out-of-school family learning.

Collections Care/Tourism— The Harriet Beecher Stowe Center (Hartford, CT) was awarded $150,000 to preserve and protect the collections of this 1871 historic house, an international heritage tourism site.

Teacher Training— The Mystic Seaport Museum (Mystic, CT) was awarded $80,343 for cataloging and digitizing 4,950 items to support an online learning project for students and to provide teacher training.

I am aware that this subcommittee wants to ensure that its investments in federal grant programs have measurable and significant impact. I believe that the grants listed above demonstrate the value of investing in museums as a means of investing in our communities. Further, it should be noted that each time a federal grant is

awarded, additional local and private funds are also leveraged. Two-thirds of IMLS grantees report that their Museums for America grant had positioned the museum to receive additional private funding.

Even the most ardent deficit hawks view the IMLS grant-making process as a model for the nation. Each grant is selected through a rigorous, peer-reviewed process. And due to the large number of grant applications and the limited funds available, many highly-rated grant proposals go unfunded each year.

- Only 28% of Museums for America/Conservation Project Support project proposals were funded;
- Only 15% of National Leadership project proposals were funded;
- Only 15% of Sparks Ignition Grants for Museums project proposals were funded;
- Only 46% of Native American/Hawaiian Museum Services project proposals were funded; and
- Only 31% of African American History and Culture project proposals were funded.

On a final and personal note, the interviews I conduct with museum professionals for my television show have confirmed for me what I've known since I was a kid—that museums are cool, *really* cool. If there's one thing Americans young and old love, it's a good story about America and that's what museums have to offer.

American museums do this job and they do it extremely well. They collect the stories by preserving and curating the objects—documents, inventions, clothing, paintings, sculptures and skeletons—which explain who we've been, who we are and how we survive.

I was raised outside of Philadelphia. Without museums, I'd have never walked through the left ventricle of the super-sized heart in the Ben Franklin Institute. But for the Academy of Natural Sciences, I'd have never understood the difference between a stegosaurus and a triceratops. I wouldn't have had that first encounter with Vincent van Gogh at the Philadelphia Museum of Art. It's impossible to imagine my childhood without museums or to imagine my adulthood. They're our lifeline to the past—and an inspiration for the future.

We hope you'll support our cause, and provide at least $38.6 million in fiscal year 2015 for the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), its fully-authorized amount.

Anthony R. Sarmiento, Executive Director
Senior Service America, Inc.

Statement for the Record Submitted to
House Committee on Appropriations Subcommittee
on Labor, Health and Human Services, Education and Related Agencies

This statement concerns the Administration's proposed FY15 appropriations of $380 million for the Department of Health and Human Services – Administration for Community Living's Senior Community Service Employment Program. We urge that funding for this program be increased to $600 million, returning the program to its funding levels prior to the Great Recession (adjusted for inflation). This investment would provide jobs and training for more than 30,000 additional unemployed older Americans than the Administration's proposal. We also urge that the Congress refer to the authorizing committee any proposals to revise the mission of the program or transfer the program from the Department of Labor.

The Senior Community Service Employment Program (SCSEP) is the only federal program targeted to provide jobs and training to low-income older adults 55 and older. According to GAO Report GAO-11-92, SCSEP is one of only three federal workforce development programs that do not overlap with any other program. Launched in 1968, SCSEP is authorized by Title V of the Older Americans Act and is currently administered by the Department of Labor Employment and Training Administration. In the year ending June 30, 2013, SCSEP provided jobs and training for 67,551 economically disadvantaged older adults, who in turn provided over 37.2 million hours of staffing to 30,000 local private and private nonprofit agencies serving the community. The value of these community service hours was $825 million, based on hourly-wage estimates from the Independent Sector.

The Administration's FY15 budget proposes to cut funding for SCSEP to $380 million, $54 million less than $434 million enacted for FY14. Senior Service America estimates that this cut would result in almost 9,000 fewer jobs and training nationwide for low income older adults and 4.7 million fewer staff hours in local agencies (whose value exceeds $105 million).

The following facts strongly support increasing the appropriations for SCSEP in FY2015:

1. **Low-income older workers, most of whom are long-term unemployed, continue to suffer extremely high rates of joblessness**. As the following table shows, since 2000 the jobless rate of low-income older workers (55 years and older with annual family incomes less than $20k) has been 2.5 to 3 times higher than the rate among all older workers:

Year	Unemployment rate for low income older workers	Unemployment Rate of All 55+
2000	6.6%	2.6%
2001	7.6%	3.0%
2002	9.7%	3.8%
2003	11.1%	4.0%
2004	10.6%	3.7%
2005	10.1%	3.4%
2006	9.9%	3.0%
2007	10.0%	3.1%
2008	11.8%	3.8%
2009	18.8%	6.6%
2010	19.9%	7.0%
2011	19.5%	6.5%
2012	18.4%	6.0%
2013	17.0%	5.8%

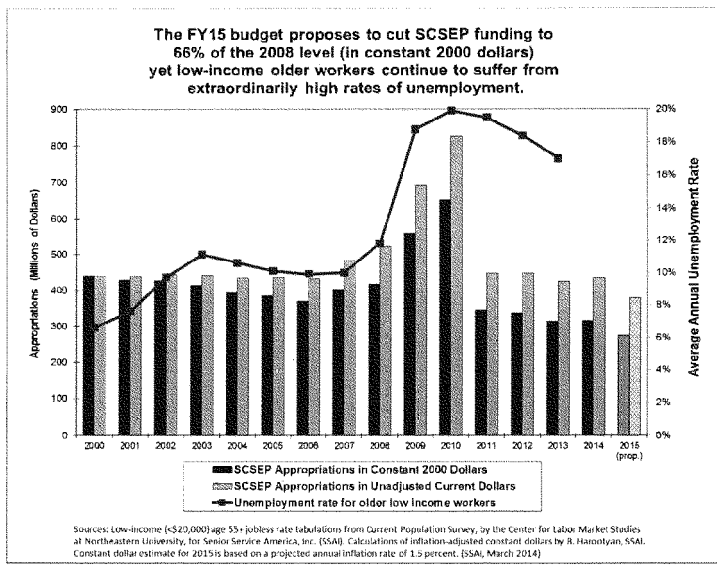
Source: Low-income (<$20,000) age 55+ jobless rate tabulations from Current Population Survey, by the Center for Labor Market Studies, Northeastern University, for Senior Service America, Inc., January 2014.

2. **SCSEP is a unique employment and training program of the Federal government**, cited in the previously mentioned 2011 GAO report as one of only three federal workforce programs "that do not overlap with other programs." It also assists a harder-to-serve segment of the older adult workforce: 88% of participants were at or below the

poverty level; 60% were at least 60 years old; nearly two-thirds were women; and over half of the participants were from a racial/ethnic minority (PY2012).

3. **SCSEP grantees succeed in carrying out the Congressional intent for the program.** According to an independent national evaluation conducted by Mathematica Policy Research (MPR) and Social Policy Research Associates (SPR) in 2012 for the U.S. Department of Labor, "SCSEP projects are largely successful in recruiting and enrolling older workers with serious barriers to employment, providing participants with community service assignments at host agencies, and [annually] placing nearly half of program exiters who are available for work into unsubsidized jobs."
4. **Programs under the Workforce Investment Act (WIA) continue to underserve older workers.** Several GAO reports have cited that WIA performance measures may create disincentives for serving older workers seeking part-time work. As a result, a disproportionately small percentage of those served by American Job Centers are older workers. The 2012 MPR/SPR evaluation of SCSEP stated that "SCSEP projects find it difficult to draw on the resources of American Job Centers to support participants in finding jobs."
5. **The value of work performed by SCSEP participants in their community service assignments is nearly double the total amount appropriated for SCSEP.** In PY2012, SCSEP participants worked over 37 million hours at minimum wage in over 30,000 host agencies (nonprofit, faith-based, and public), including more than 10 million hours serving other older persons through Meals on Wheels, area agencies on aging, and other organizations. Using the Independent Sector's estimated hourly value of volunteer work, the estimated value of this community service was nearly $825 million.

6. **The FY15 budget proposes to cut SCSEP funding to 66% of the 2008 level (in constant 2000 dollars), yet low-income older workers continue to suffer from extraordinarily high rates of unemployment.** The following graph shows the unemployment rate among low-income older workers since 2000 (described in the previous table on page 2) in contrast to the history of SCSEP funding, in both current dollars and constant 2000 dollars. In 2008, the average annual unemployment rate for low-income older adults 55 and over was 11.8% and SCSEP funding was $521.6 million (unadjusted) or $417.2 million (in constant 2000 dollars). In unadjusted dollars, the proposed FY15 budget for SCSEP of $380 million represents 73% of the 2008 funding for SCSEP, but the FY15 budget would cut SCSEP to only 66% of the 2008 funding in constant dollars—yet the average annual unemployment rate for the SCSEP-eligible population is about 17% in 2013 compared to less than 12% in 2008.



The following table shows the history of SCSEP funding since 2000:

Fiscal Year	Final Appropriations in Current Dollars (millions)	Real Value of Annual Appropriations in Constant Dollars (Base Year: 2000)
2000	440.2	440.2
2001	440.2	428.0
2002	445.1	426.1
2003	442.3	413.9
2004	434.0	395.7
2005	436.7	385.0
2006	432.3	369.3
2007	483.6	401.6
2008	521.6	417.2
2009	691.9	558.4
2010	825.4	651.8
2011	449.1	343.8
2012	448.3	336.2
2013	424.8	313.9
2014	434.4	318.6
2015 (proposed)	***380.0***	***274.6 (est)***

Note: Estimation Procedure for 2015 Constant Dollar Value (base year = 2000):
Estimated Cumulative Inflation Index (CII) for 2015 is based on projected annual inflation rate of 1.5%.
OMB proposed SCSEP appropriation for FY2015 = $380m.
FY2015 $380m = $278.7m in 2014 constant dollars. The CII through 2014 = $380/$278.7 = 1.3635.
Estimated CII for 2015 (based on 1.5% inflation rate) = 1.3635 + (1.3635 x 0.015) = 1.3840.
FY2015 proposed $380m appropriation = $380m / 1.3840 = $274.57m in constant dollars (base year 2000).

Our economy continues to leave millions of low-income older Americans behind. SCSEP remains the only federal program targeted to help them re-enter the workforce and enhance their health and well-being. These older workers help expand the capacity of local agencies to meet the basic needs of their communities. In an independent national survey of 10,000 of these agencies, 75% reported that SCSEP significantly or somewhat increased their ability to provide services. In sum, SCSEP is a unique program that achieves a wide range of outcomes and produces multiple returns on investment. Throughout the nation, older Americans and communities need and depend on the Senior Community Service Employment Program.

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National Primate Research Centers
Written Statement for the Record
March 28, 2015

Prepared for the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives
On
Fiscal Year 2015 Funding for the National Institutes of Health

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 support for the National Institutes of Health (NIH) and **recommend $32 billion for NIH in fiscal year (FY) 2015**. The NPRCs also respectfully request that the Subcommittee provide strong support for the NIH Office of Research Infrastructure Programs (ORIP), housed within the NIH Office of the Director, which is the administrative home of the NPRCs. This support would help to ensure that the NPRCs and other animal research resource programs continue to serve effectively in their role as vital national resources.

The mission of the NPRCs is to use scientific discovery and nonhuman primate models to accelerate progress in understanding human diseases, leading to interventions, treatments, cures, and ultimately to overall better health of the nation and the world. The NPRCs collaborate as a transformative and innovative network to develop and 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 and to continue to grow and develop the innovative plan for the future of NIH.

The Consolidated Appropriations Act of 2014 provided a welcome and much needed increase for the NIH. However, this increase did not give back all of the funds cut by sequestration in FY 2013 nor did it restore the purchasing power NIH has lost over the past decade. At the same time that scientists are facing these funding challenges, they are poised as never before to capitalize on tremendous scientific opportunities and make paradigm-shifting discoveries to address our nation's most pressing public health needs. Budget uncertainty is disruptive to training, careers, long-range projects, and ultimately, to research progress. To ensure the successful and efficient advancement of science, the research engine needs predictable, sustained funding that maximizes the nation's return on investment.

The NPRCs hope FY 2014 represents a first step toward restoring our nation's preeminence in medical research and urge Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our nation's health, and jeopardize our economic future.

NPRCs' Contributions to NIH Research Priorities

The NPRCs' activities are closely aligned with NIH priorities. In fact, NPRC investigators conduct much of the nation's basic and translational nonhuman primate research, facilitate additional vital nonhuman primate research that is conducted by hundreds of investigators from around the country, provide critical scientific expertise, train the next generation of scientists, and advance cutting-edge

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technologies. It is neither cost effective nor feasible to reproduce these specialized facilities and expertise at every research institution, so the NPRCs are a valuable resource to the research community. As a part of the NIH Office of the Director, the NPRCs work with all NIH institutes and centers to further integrate the consortium as a trans-NIH resource on topics such as colony management, training, genetics and genome banking and research areas such as stroke, Alzheimer's disease, HIV/AIDS, autism, hepatitis, obesity, behavioral health, respiratory illnesses, reproductive health, biodefense, influenza, and numerous others. Below are examples of promising research at NPRCs.

- An experimental vaccine modeling human cytomegalovirus (HCMV) infection—which can endanger developing fetuses, transplant recipients, patients co-infected with HIV and others who have a weakened immune system — proved safe and effective in research conducted at the **California National Primate Research Center** using the Rhesus macaque model. A team of scientists led by CNPRC researchers developed the first-of-its-kind approach to preventing HCMV infection by inducing broader immunological protection in Rhesus monkeys. Development of an HCMV vaccine has been ranked as a highest priority by the Institute of Medicine.
- Scientists at the **New England Primate Research Center** are taking advantage of the genetic similarity between rhesus monkeys to humans to create the first monkey model of alcoholism genetics. Studies in human alcoholics who are treated with naltrexone, a leading medication for alcohol dependence, have shown that the medication works better in people who have a specific genetic variant in the OPRM1 gene. Scientists at the NEPRC identified a similar genetic change in the rhesus monkey OPRM1 gene, and have shown that monkeys with the genetic change not only drink more alcohol but also have a comparable genetically-determined response to naltrexone to that seen in some human alcoholics. This animal model gives scientists a new way to create personalized medications for the treatment of alcoholism.

NATIONAL PRIMATE RESEARCH CENTERS

- A senior **Oregon National Primate Research Center** scientist has been able to make embryonic stem cells from adult mouse body cells using the cytoplasm of two-cell embryos that were in the "interphase" stage of the cell cycle. These findings could have major implications for the science of generating patient-matched human embryonic stem cells for regenerative medicine, which would hold promise for someday curing or treating a range of diseases and conditions – from Parkinson's disease to cardiac disease to spinal cord injuries — by replacing cells damaged through injury or illness.
- Research with baboons at the **Southwest National Primate Research Center** may help explain why some people who take bone-strengthening drugs like bisphosphonates are at risk for atypical fractures in the long bones in their legs. The study supports the theory that genetic variations may regulate bone remodeling, a natural process during which mature bone tissue is removed from the skeleton so that new tissue can be added. These genetic differences could explain why a small percentage of older women suffer a distinct type of fracture of their femurs when they take bisphosphonates, a type of medication prescribed for millions of people with the bone-weakening disease osteoporosis.
- A new study conducted by the **Tulane National Primate Research Center** shows that injections of a novel long-acting AIDS drug protected monkeys against infection with a virus similar to HIV. Researchers at the Tulane National Primate Research Center exposed 16 rhesus macaque monkeys to human-simian immunodeficiency virus. Half the monkeys received monthly injections of the new drug, GSK744, and the other half were untreated. The results were striking: all the monkeys injected with the drug were protected, but those that did not receive the drug became infected. These pre-clinical animal studies give strong support to advancing to clinical testing of GSK744 in humans as a next-generation HIV prevention drug.
- Recovery of function after stroke, traumatic brain injury or spinal cord injury is a significant medical challenge for millions of patients in the U.S. A promising new treatment for many of these disabled survivors is an implantable recurrent brain-computer interface (R-BCI). The **Washington National**

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Primate Research Center has developed the implantable R-BCI, a "neurochip" that records neural activity from the brain and transforms that activity into stimuli delivered to the brain, spinal cord, or muscles during free behavior. R-BCI technology has the clinical potential to aid patients paralyzed by ALS or spinal cord injury to regain some motor control directly from cortical cells and may also be used to strengthen weak connections impaired by stroke.

- In an experiment that is a proof-of-principle for personalized medicine, scientists at the **Wisconsin National Primate Research Cente**r transplanted neural cells derived from a monkey's skin into its brain and watched the cells develop into several types of mature brain cells. While the transplant technique is a long way from the clinic, it represents a real first step toward personalized regenerative medicine treatments for patients suffering from Parkinson's and other diseases.
- Supported by NIH grants, the **Yerkes National Primate Research Cente**r has developed a behavioral assay called the Visual Paired Comparisons (VPC) task, a benchmark test both for diagnosing Mild Cognitive Impairment and Alzheimer's disease, and most importantly for predicting the onset of cognitive decline three to five years prior to any clinical symptoms. Researchers have been working on automated versions of the task using nonhuman primate subjects, and a recent NIH award is focused on the development of a web-based version of the VPC task, which will allow anyone, anywhere in the world with access to a computer to take the test and have the results sent electronically to a physician for interpretation.

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. We thank you for your support of NIH and urge you to provide the agency $32 billion in the FY 2015 appropriations bill.

Association of American Cancer Institutes

Statement by the Association of American Cancer Institutes on
FY 2015 Appropriations for the Department of Health and Human Services
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations, U.S. House of Representatives

Testimony submitted by:
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The Association of American Cancer Institutes (AACI), representing 92 of the nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the subcommittee. AACI submits this request for the Department of Health and Human Services budget for the National Institutes of Health (NIH) in the amount of $32 billion for FY 2015.

AACI thanks Congress for its long-standing commitment to ensuring quality care for cancer patients, as well as for providing researchers with the resources that they need to develop better cancer treatments and, ultimately, to find cures for this deadly disease. The partnership between the federal government and our nation's cancer centers is mutually beneficial, and cancer centers continue to make strides in biomedical research thanks to the support of the federal government. Without such support, research projects with the potential to discover breakthrough therapies would not be possible.

The President's Fiscal Year (FY) 2015 budget proposes $30.2 billion for the NIH, an increase of $200 million (0.7 percent) over the FY 2014 level. This amount includes $4.931 billion for the National Cancer Institute (NCI), a $7.5 million increase over FY 2014 (0.2 percent). Though we appreciate the president's support, NIH and NCI continue to endure a lag in funding. The FY 2015 proposal falls far short of the inflation rate of 2.9 percent, a figure that NIH projected last year for the Biomedical Research and Development Price Index (BRDPI) for FY 2015. AACI joins with our colleagues in the biomedical research community in recommending that the subcommittee recognize NIH as a critical national priority by providing at least $32 billion in funding in the FY 2015 Labor-HHS-Education Appropriations bill,

including an equivalent percentage increase in funding for NCI. This funding level represents the minimum investment necessary to avoid further loss of promising research.

Cancer Centers Must Be Supported in Order to Move Research Forward

America's standing in research and scientific discovery is threatened with each dollar slashed from the NIH budget. The budgetary pain in FY 2014 has been less intense than in recent years but still remains for cancer centers striving both to keep gifted scientists at their institutions and to resume halted research projects due to sequestration. For some labs, recovery is nowhere in sight. Many have closed their doors, while some scientists have taken early retirement or simply left the field. Even some well-established labs claim they will never recover from the damage caused by sequestration.

With cancer centers challenged to provide infrastructure resources necessary to support researchers, the failure to keep pace with the biomedical inflation rate will limit AACI members' ability to provide well-functioning shared resources to investigators who depend on them to complete their research. For most academic cancer centers, the majority of NCI grant funds are used to sustain shared resources that are essential to basic, translational, clinical and population cancer research, or to provide matching dollars which allow departments to recruit new cancer researchers to a university and support them until they receive their first grants. Center infrastructure is expensive and it is not clear where cancer centers would acquire alternative funding if NCI grants for these efforts dwindle.

AACI cancer centers are at the forefront of the national effort to eradicate cancer. The cancer centers that AACI represents house more than 20,000 scientific, clinical and public health investigators who work collaboratively to translate promising research findings into new approaches to prevent and treat cancer. Making progress against cancer is complex and time-intensive. However, the pace of discovery and translation of novel basic research to new therapies could be quickened if researchers could count on an appropriate and predictable investment in federal cancer funding. As research costs and patient need increase, cancer centers continue to be highly dependent on federal cancer center grants.

Cancer Centers Are Pioneers in Research

The negative effects of diminished biomedical research funding reach beyond the lab as AACI cancer center directors have vocalized their concerns. The impact of flat funding to the NIH continues to disturb advances in biomedical research and is of paramount concern to cancer center leaders.

While AACI President Michelle M. Le Beau, PhD, director of the University of Chicago Comprehensive Cancer Center, applauded the president's budget proposal, she asked that Congress build upon that budget. Dr. Le Beau has said that at a time when cancer centers continue to address the losses sustained due to budget sequestration, research institutions rely on robust aid from their partnership with the federal government. She said, "Cancer centers have served as pioneers in biomedical research, improving patient care and gaining a deeper understanding of the molecular basis of cancer through research. Advances in science are within reach, but without sufficient funding at the NIH and ultimately, the NCI, such progress in research will move at a slower pace."

Speaking at a meeting of the AACI Government Relations Forum in Houston, TX, University of Texas MD Anderson Cancer Center president Ronald DePinho, MD, echoed Dr. Le Beau's concerns. Dr. DePinho underscored the need for increased federal funding for cancer research, noting that cancer incidence in the U.S. is projected to increase 45 percent between today and 2030. Dr. DePinho has acknowledged that the major solutions for patients will come from scientific innovations that will lead to transformation in cancer prevention, early detection and definitive cures. He said that academic medical centers are the engines for such discoveries. Dr. DePinho stressed that it is "critical that we vigorously support these national treasures to deal with the onslaught of people who will need cancer services."

Robert S. DiPaola, MD, director of Rutgers Cancer Institute of New Jersey, knows the strides that can be made within cancer research due to increased NIH funding. Recently, Rutgers was awarded a competitive grant by the NCI to support their precision experimental therapeutics endeavor. Dr. DiPaola was proud to announce their collaboration with investigators from the University of Wisconsin Carbone Cancer Center as well as with a network of cancer centers. Though Dr. DiPaola and his team are grateful for the NCI funding that has made this work possible, they are increasingly aware that without adequate

increases to NIH funding, the future of cancer research collaboration could suffer. He asserted that, "Ensuring that NIH acquires an increase at least relative to the inflation rate of 2.9 percent will help to keep the progress we are making in cancer research nationwide moving in the right direction."

Samir N. Khleif, MD, director of GRU Cancer Center at Georgia Regents University, testified before the appropriations subcommittee on March 25, noting that decades of sustained strong investment in NIH and NCI have sparked remarkable progress in cancer research and treatment. Dr. Khleif asked for increased funding at the NIH and the NCI in order to "keep our best and brightest minds focused on developing the biomedical research breakthroughs that save lives." He requested that support for NIH not falter in order for the U.S. to maintain its global edge in scientific discovery and innovation and maintain its progress in reducing the burden of cancer and other diseases.

AACI President-Elect George Weiner, MD, director of the Holden Comprehensive Cancer Center at the University of Iowa, agreed with Dr. Khleif's testimony. Dr. Weiner's greatest concern stems from the decrease in funding for the NIH and the NCI and the impact reduced federal funding will have on young scientists and he has blogged about scientific and budgetary concerns. Dr. Weiner fears young scientists might not chose to conduct their research in the U.S. in the future, instead opting to go overseas as U.S. support for innovation has been flat or dropped and other countries begin to make progress. Dr. Weiner knows that the U.S. remains the world leader in biomedical research, but feels that "ongoing success will be dependent on outstanding physicians and scientists, born here and abroad, having the collaborative culture, resources and infrastructure needed to accelerate progress toward our shared mission of reducing the burden of cancer." Dr. Weiner stated that providing these tools will have a positive impact on our nation's ability to care for patients, our ability to conduct research, and our economy. Dr. Weiner stressed the need to continue to emphasize the importance of investing in innovation through education and research. He maintained that a commitment to investing in the NIH and the NCI is vital to the successes achieved through science.

Cancer Research is Improving America's Health

The broad portfolio of research supported by NIH and NCI is essential for improving our basic

understanding of diseases and has paid off considerably in terms of improving Americans' health. The five-year relative survival rate for all cancers diagnosed between 2002 and 2008 is 68 percent, up from 49 percent in 1975-1977. In addition, cancer death rates have dropped 11.4 percent among women and 19.2 percent among men over the past 15 years. [1] The improvement in survival reflects both progress in diagnosing certain cancers at an earlier stage and better treatment.

Despite that success, cancer remains the second leading cause of death in the U.S., with almost 1,600 deaths per day. More than 1.6 million new cancer cases will be discovered in 2014 and over 580,000 cancer deaths are expected.[2] NCI estimates that 41 percent of individuals born today will receive a cancer diagnosis at some point in their lifetime. [3]

Conclusion

NIH estimates that the overall costs of cancer in 2008 were $201.5 billion: $77.4 billion for direct medical costs (total of all health expenditures) and $124 billion for indirect mortality costs (cost of lost productivity due to premature death). [4] The cost of cancer continues to rise, but the investment in cancer research will one day eliminate such economic burdens on Americans and the cancer center researchers who work tirelessly to find a cure for this deadly disease. Failure to keep pace with the biomedical rate of inflation will only hinder our nation's cancer center researchers from grasping future knowledge that will aid in the prevention, detection and treatment of cancer.

As Congress makes difficult appropriations decisions for FY 2015 and beyond, AACI asks that it recall that the nation's financial support of NIH and NCI has paid dividends by introducing innovative therapies for cancers that years ago cut short far too many American lives. The future of scientific discovery in cancer research is in the hands of the scientists whose research is conducted in labs across the country. NIH's full support of NCI-designated centers and their programs remains a top priority for our nation's research institutions and we ask that Congress aid our nation's cancer centers in their goal to eradicate cancer.

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[1] American Cancer Society. Facts and Figures, 2014. http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2014/
[2] American Cancer Society. Facts and Figures.
[3] *Cancer Trends Progress Report – 2011/2012 Update*, National Cancer Institute, NIH, DHHS, Bethesda, MD, August 2012, http://progressreport.cancer.gov.
[4] American Cancer Society. Facts and Figures.

Peter T. Wilderotter *President & CEO*

Testimony of Peter T. Wilderotter
President and CEO, Christopher & Dana Reeve Foundation
United States House of Representatives
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations

March 28, 2014

On behalf of the Christopher & Dana Reeve Foundation, 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.

Founded in 1982, the Christopher & Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research and improving the quality of life for the nearly 6 million Americans living with paralysis through grants, information and advocacy. Since its inception, the Foundation has provided $110 million in research grants to more than 750 researchers, and has awarded over 2,300 grants totaling more than $17 million to organizations across the country through our Quality of Life grants program.

I would like to take this opportunity to specifically thank the Subcommittee for their continued investment in the Christopher & Dana Reeve Foundation Paralysis Resource Center (PRC). Formed through a cooperative agreement with the federal government, the PRC provides a comprehensive, national source of information for people living with paralysis and their families to promote health, foster involvement in the community, and improve quality of life.

The PRC is making a difference in the daily lives of those living with spinal cord injury and paralysis and we are seeing real results. The PRC provides services and information to over 500,000 individuals annually, including access to state-of-the-art therapies focused on improving health and mobility; guidance for evaluating rehab facilities and redesigning a home to make it wheel chair accessible; referrals to community support programs; and information and resources on a full range of topics related to paralysis and issues that arise from secondary complications.

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The PRC has provided hundreds of thousands of individuals and families living with paralysis with useful, often life-saving and life-changing information and therapies. The PRC also supports the Christopher & Dana Reeve Foundation NeuroRecovery Network (NRN) which is a group of thirteen innovative rehabilitation centers that develop and deploy therapies to promote functional recovery and improve the health and quality of life for people living with paralysis.

The PRC was founded in 2002 through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) and has evolved into one of the foremost programs for improving quality of life, fostering community involvement, and promoting the health and well-being of people living with paralysis. While incredibly proud of all that has been accomplished at the CDC, the Foundation is grateful for the support of this Committee as we transfer to our new home at the Administration for Community Living (ACL).

Formed in 2012, the ACL merged the Department of Aging and the Department of Disability. The ACL's mission, to "maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers," aligns with the PRC's efforts to champion the health and quality of life of those living with paralysis.

With the ACL's support, the PRC will serve as the anchor for the mobility impairment community and be able to evolve and expand current programs to reach a wider network across the country. Together, the PRC and ACL will strive to support optimal care for the mobility impairment community and those that care for them by promoting health, encouraging greater community engagement, and improving quality of life throughout their lifespan.

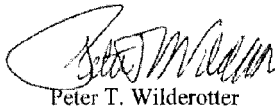
In this new role the Foundation looks forward to working with ACL to reduce barriers for the mobility-impaired and encourage full independence and participation in community. This transition will provide an opportunity to expand current PRC programs and to develop new policies that will ensure

those living with disability have the programs and services they need to live with independence throughout their life course.

We appreciate the difficult funding decisions Congress is faced with this year given the challenging budget climate. It is my hope, that in these challenging times, we can continue to work with the Subcommittee to ensure continued investment in the programs and agencies that have the greatest impact for the disability community.

Thank you, Mr. Chairman and Members of the Subcommittee, for the opportunity to submit my testimony.

Respectfully submitted,



Peter T. Wilderotter

Lindsay E. Jones, Esq.
Director, Public Policy and Advocacy
National Center for Learning Disabilities

Written testimony submitted to the U.S. House of Representatives Committee on Appropriations

March 28, 2014

The National Center for Learning Disabilities (NCLD) works to ensure that the nation's 60 million children, adolescents and adults with learning disabilities and attention issues have every opportunity to succeed in school, work and life. NCLD asks you to consider our request as you work on the fiscal year 2015 Labor, Health and Human Services, and Education Appropriations bill.

As you begin work on the fiscal year 2015 Labor, Health and Human Services, and Education Appropriations bill, we urge you to support continued funding for special education at the President's request level of $11.57 billion for the Individuals with Disabilities Education Act (IDEA) and the President's $100 million for Results Driven Accountability Incentive Grants which would provide competitive grants to states to implement promising, evidence-based reforms that would improve service delivery for children with disabilities while building state and local capacity to improve long—term outcomes for those children

We also urge you to support funding for the National Technical Assistance Center within the Higher Education Opportunity Act (Section 777(a)) at $2 million to provide useful and comprehensive information to students with disabilities on the choices available to them in higher education and to provide much-needed training, technical assistance, and professional development to institutes of higher education.

IDEA Part B Grants to States & Results Driven Accountability Incentive Grants

Currently, there are over 6.5 million children eligible for special education services under the disability categories of the Individuals with Disabilities Education Act (IDEA). The comprehensive assessment and support services authorized by IDEA help to close the academic achievement gap and ensure a meaningful education for every student. We owe it to all students to provide a quality education that will help them graduate and enter successful careers.

We support the Administration's request that would maintain funding for IDEA, Part B (Grants to States program) at $11.57 billion, which the Administration estimates would provide $1,758 per child for an estimated 6.6 million students with disabilities. Additionally we support the President's $100 million for Results Driven Accountability Incentive Grants, which would provide competitive grants to states to implement promising, evidence-based reforms that would improve service delivery for children with disabilities. We encourage innovation in the realm of service delivery to students receiving special education and believe that these grants have the potential to spark innovative ideas and a renewed focused on improved outcomes for students.

The National Technical Assistance Center

In the HEA reauthorization of 2008, Congress authorized the establishment of National Center for Information and Technical Support for Postsecondary Students with Disabilities. This Center was intended to serve three primary purposes: (1) serve as a resource to parents and students with disabilities on the services available at various IHEs; (2) serve as a technical assistance center to IHEs and provide training to faculty and staff on how to improve services for students with disabilities; and (3) serve as an online database for the collection and dissemination

of a variety of disability-related information for students with disabilities who are interested in higher education. Though the Center was authorized, it has never been funded.

How Students with Disabilities are Faring in Higher Education

In recent years, due to the services provided to students with disabilities through the Individuals with Disabilities in Education Act (IDEA) or Section 504 of the Rehabilitation Act, students with learning and attention issues have graduated from high school at higher rates than ever before. In fact, a majority (54 percent) of students with learning disabilities have the goal to attend a two- or four-year college.[1] Students with learning disabilities make up the largest population of students with disabilities who attend postsecondary schools, at 69 percent of all students with disabilities in postsecondary programs.[2]

Unfortunately, students with disabilities are not attending postsecondary education programs at the same rate as students in the general population. In the general education population, within four years of graduating high school, 53 percent of students continue on to postsecondary education programs, compared to only 45 percent of youth with disabilities. Even worse, young adults with learning disabilities (LD) attend four-year colleges at half the rate of the general population.[3] Students with disabilities would benefit from better outreach, recruitment, and assistance programs to bridge the gap between high school and postsecondary education programs. Comprehensive information on higher education programs and services is needed now more than ever. With more students with disabilities setting goals of attending college but few actually enrolling and completing college programs, it is critical that they have access to the information and support services they need.

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[1] Cortiella, Candace and Horowitz, Sheldon H. *The State of Learning Disabilities: Facts, Trends and Emerging Issues.* New York: National Center for Learning Disabilities, 2014.
[2] Newman, L.A. & Madaus, J. W. (2013). Reported Accommodations and Supports Provided to Seeondary and Postsecondary Students with Disabilities: National Perspective. *Publication forthcoming.*
[3] Cortiella & and Horowitz (2014).

The Lack of Comprehensive Information on Post-Secondary Education Programs

The U.S. Department of Education (ED) has made efforts to improve parent and student access to timely and useful information regarding colleges and universities through the development of the College Navigator. The Department of Education collects data from IHEs through Integrated Postsecondary Education Data System (IPEDS) surveys, including data on enrollment, program completion, graduation rates, faculty and staff, finances, institutional prices, and student financial aid. The data is made available to students and parents via College Navigator – a public website that allows users to perform a search of colleges. The data and information provided through the College Navigator – has the potential to support and improve rates of transition for all young adults from high school into the postsecondary setting. However, this information alone is not enough to ensure a smooth transition for students with disabilities into their postsecondary education programs.

NCLD has conducted its own survey of the information provided by IHEs on College Navigator. College Navigator provides a place for every IHE to provide information on the disability services offered at the institution. We examined the responses that nearly 400 institutions submitted, including private, public, and for profit institutions as well as community colleges. Only 6 of the institutions surveyed listed any information to students and the public regarding disability services.[4]

The Need for a Smoother Transition to Post-Secondary Programs

Research shows that students with disabilities are getting less support in college than in high school, despite wishing they had more assistance. Even though 87 percent of students with disabilities received some type of accommodation or support in high school, that number drops

[4] For more information on the survey conducted by NCLD and the IHEs we surveyed to find this data, please contact us.

off sharply when students with disabilities enter college, decreasing to only 19 percent of students who receive accommodations or support.[5] For students with learning disabilities, 17 percent of young adults receive accommodations and supports in postsecondary education compared with 94 percent in high school.[6] Of the many students who did not receive any help at all, 43 percent felt that it would have been helpful to receive assistance.[7] We know that self-advocacy is one of the keys to student success, but it is clear that students are not aware of their rights and responsibilities, are not adequately prepared to advocate for themselves, and are not provided adequate transition assistance to be successful in postsecondary education programs.

The Purpose of the National Technical Assistance Center

We recognize that providing useful and comprehensive information to parents and students on the choices available is not an easy task. Therefore, we recommend funding the National Technical Assistance Center, found in the 2008 authorization of HEA, at $2 million. The Center would serve several key purposes: (1) providing information and resources to students and parents on disability services and programs at IHEs; (2) providing training and technical assistance to IHEs; (3) providing training and professional development to faculty and staff at IHEs; and (4) information collection and dissemination on best practices, documentation requirements, financial aid, services available, policies, and accessible instructional materials.

We urge you to continue your investment in students with disabilities through funding of IDEA and the RDA grants and support funding in fiscal year 2015 for the National Technical Assistance Center. Thank you for your consideration of our request.

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[5] Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., et al. (2011). The PostHigh School Outcomes of Young Adults With Disabilities up to 8 Years After High School. A Report From the National Longitudinal Transition Study-2 (NLTS2) (NCSER 2011-3005). Menlo Park, CA: SRI International.
[6] Cortiella & and Horowitz (2014).
[7] Newman, Wagner, Knokey, Marder, Nagle, et al. (2011).

Testimony of the Nursing Community Regarding
Fiscal Year (FY) 2015 Appropriations for the Title VIII Nursing Workforce Development Programs, the National Institute of Nursing Research, and Nurse-Managed Health Clinics

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

Department of Health and Human Services

March 28, 2014

Submitted by Suzanne Miyamoto, Convener of the Nursing Community

The Nursing Community is a forum comprised of 60 national professional nursing associations that builds consensus and advocates on a wide spectrum of healthcare and nursing issues surrounding practice, education, and research. These organizations are committed to promoting America's health through the advancement of the nursing profession. Collectively, the Nursing Community represents nearly one million Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs-including certified nurse-midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists), nurse executives, nursing students, nursing faculty, and nurse researchers. For FY 2015, our organizations respectfully request $251 million for the Health Resources and Services Administration's Nursing Workforce Development programs (authorized under Title VIII of the *Public Health Service Act* [42 U.S.C. 296 et seq.]), $150 million for the National Institute of Nursing Research (NINR) within the National Institutes of Health (NIH), and $20 million in authorized funding for the Nurse-Managed Health Clinics (Title III of the *Public Health Service Act*). These investments will help ensure that our nation's population receives the highest-quality nursing services possible.

Demand for Nurses Continues to Grow

According to the Bureau of Labor Statistics' (BLS) *Employment Projections for 2012-2022*, the expected number of practicing nurses will grow from 2.71 million in 2012 to 3.24 million in 2022, an increase of 526,800, or 19.4%. The number of job openings due to demand for registered nursing services and replacements brings the total of RNs needed to 1.053 million by 2022. In addition, nurse practitioners are one of the fastest growing occupations according to the BLS projections, noting there will be a 33.7% increase between 2012-2022.

Two primary factors contribute to this overwhelming projection. First, America's nursing workforce is aging. A 2013 HRSA report *The U.S. Nursing Workforce: Trends in Supply and Education* indicates that over the next 10 to 15 years, the nearly one million RNs over age 50 (comprising approximately one-third of the current workforce), will reach retirement age. Secondly, America's Baby Boomer population is aging. This population will require a vast influx of nursing services, particularly in areas of primary care and chronic illness management. A significant investment must be made in the education of new nurses to provide the nation with the nursing services it demands.

Addressing the Demand: Title VIII Nursing Workforce Development Programs

For 50 years, the Nursing Workforce Development programs, authorized under Title VIII of the *Public Health Service Act*, have helped build the supply and distribution of qualified nurses to meet our nation's healthcare needs. 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. Today, the Title VIII programs are essential to ensure the demand for nursing care is met. Between FY 2005 and 2012 alone, the

Title VIII programs supported over 450,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities.

The American Association of Colleges of Nursing's (AACN) *Title VIII Student Recipient Survey* gathers information about Title VIII dollars and its impact on nursing students. The 2012-2013 survey, which included responses from over 800 students, stated that the Title VIII programs played a critical role in funding their nursing education. The survey showed that 78% 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 Title VIII programs also address the need for more nurse faculty. Data from AACN's 2013-2014 enrollment and graduations survey show that nursing schools were forced to turn away 78,089 qualified applications from entry-level baccalaureate and graduate nursing programs in 2013, and faculty vacancy was a primary reason. The Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education provided they serve as faculty for four years after graduation.

The Nursing Community respectfully requests $251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in FY 2015.

National Institute of Nursing Research: Foundation for Evidence-Based Care

As one of the 27 Institutes and Centers at the NIH, the NINR funds research that lays the groundwork for evidence-based nursing practice. Nurse-scientists at NINR examine ways to improve care models to deliver safe, high-quality, and cost-effective health services to the nation.

Our country must look toward the prevention aspect of health care as the vehicle for saving our system from further financial burden, and the work of NINR embraces this endeavor through research related to care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse-researchers, many of whom also serve as faculty in our nation's nursing schools. ***The Nursing Community respectfully requests $150 million for the NINR in FY 2015.***

Nurse-Managed Health Clinics: Expanding Access to Care

NMHCs are healthcare delivery sites managed by APRNs and are staffed by an interdisciplinary health provider team which may include physicians, social workers, public health nurses, and therapists. These clinics are often associated with a school, college, university, department of nursing, federally qualified health center, or independent nonprofit healthcare agency. NMHCs serve as critical access points to keep patients out of the emergency room, saving the healthcare system millions of dollars annually.

NMHCs provide care to patients in medically underserved regions of the country, including rural communities, Native American reservations, senior citizen centers, elementary schools, and urban housing developments. The populations within these communities are the most vulnerable to chronic illnesses that create heavy financial burden on patients and the healthcare system. NMHCs aim to reduce the prevalence of disease and create healthier communities by providing primary care services and educating patients on health promotion practices. Furthermore, NMHCs serve as

clinical education training sites for nursing students and other health professionals, a crucial aspect of NMHCs given that a lack of training sites is commonly identified as a barrier to nursing school enrollment. ***The Nursing Community respectfully requests $20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in FY 2015.***

Without a workforce of well-educated nurses providing evidence-based care to those who need it most, including our growing aging population, the healthcare system is not sustainable. The Nursing Community's request of $251 million for the Title VIII Nursing Workforce Development programs, $150 million for the National Institute of Nursing Research, and $20 million for Nurse-Managed Health Clinics in FY 2015 will help ensure access to quality care provided by America's nursing workforce.

Members of the Nursing Community Submitting this Testimony

Academy of Medical-Surgical Nurses
American Academy of Ambulatory Care Nursing
American Academy of Nursing
American Assembly for Men in Nursing
American Association of Colleges of Nursing
American Association of Critical-Care Nurses
American Association of Heart Failure Nurses
American Association of Neuroscience Nurses
American Association of Nurse Anesthetists
American Association of Nurse Assessment Coordination
American Association of Nurse Practitioners
American College of Nurse-Midwives
American Nurses Association
American Organization of Nurse Executives
American Pediatric Surgical Nurses Association
American Psychiatric Nurses Association
American Society for Pain Management Nursing
American Society of PeriAnesthesia Nurses
Association of Community Health Nursing Educators
Association of Nurses in AIDS Care
Association of periOperative Registered Nurses
Association of Public Health Nurses
Association of Women's Health, Obstetric and Neonatal Nurses
Dermatology Nurses' Association
Developmental Disabilities Nurses Association
Emergency Nurses Association
Gerontological Advanced Practice Nurses Association
Infusion Nurses Society
International Society of Psychiatric Nursing
National American Arab Nurses Association
National Association of Clinical Nurse Specialists
National Association of Pediatric Nurse Practitioners
National Association of School Nurses
National Black Nurses Association
National Forum of State Nursing Workforce Centers
National Nursing Centers Consortium
National Organization for Associate Degree Nursing
National Organization of Nurse Practitioner Faculties
Nurses Organization of Veterans Affairs
Oncology Nursing Society
Preventive Cardiovascular Nurses Association
Society of Urologic Nurses and Associates

Written Statement of The Trevor Project
Regarding Appropriations for Youth Mental Health
Submitted to the House Committee on Appropriations, March 28, 2014

For further information, contact Elliot Kennedy, Government Affairs Counsel:
Elliot.Kennedy@thetrevorproject.org

March 28, 2014

The Honorable Jack Kingston
Chairman
House Labor/Health and Human
Services Appropriations Subcommittee
2358-B Rayburn House Office Building
Washington, D.C. 20515

The Honorable Rosa DeLauro
Ranking Minority Member
House Labor/Health and Human
Services Appropriations Subcommittee
1016 Longworth House Office Building
Washington, D.C. 20515

Dear Chairman Kingston and Representative DeLauro:

The Trevor Project appreciates the opportunity to submit a statement on the critical and timely issue of funding for children's suicide prevention and mental health initiatives. We encourage you to support our nation's most vulnerable youth by funding these vital programs:

Program	FY 2014 Enacted	President's Proposed FY 2015 Budget	FY 2015 Trevor Project Recommendation
SAMHSA - Suicide Prevention Programs	$51 M	$40.1 M	$61 M
HHS/ACF - Runaway and Homeless Youth Act Funding	$114.1 M	$114 M	$152.5 M
SAMHSA – Suicide Prevention Research			$40 M
CDC – National Violent Death Reporting System	$11.3 M	$23.5 M	$25 M
SAMHSA Project AWARE	$55 M	$55 M	$60 M

The Trevor Project is the leading national organization providing crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender and questioning (LGBTQ) young people under 24. Among young people ages 10 to 24, suicide is the second leading cause of death.[1] Suicidality

[1] CENTERS FOR DISEASE CONTROL AND PREVENTION, NATIONAL CENTER FOR INJURY PREVENTION AND CONTROL, WEB-BASED INJURY STATISTICS QUERY AND REPORTING SYSTEM (WISQARS), available at http://www.cdc.gov/ncipc/wisqars (last visited Mar. 14, 2013).

is closely associated with mental illness; more than 90 percent of those who die by suicide have a diagnosable mental disorder.[2] Therefore suicide prevention is an essential component of a comprehensive mental health system.

According to the National Survey of Children's Health, up to 20% of young people have a diagnosable mental illness, but only 60% of those in need of mental health care receive the treatment they require.[3] In fact, half of all individuals with mental illness experience onset of the disorder by age 14, but do not seek treatment, on average, until the age of 24.[4] For youth, the consequences of untreated mental illness vary and include increased suicide risk, school failure, involvement in the criminal justice system, unemployment, substance abuse, and homelessness. Among stigmatized populations such as LGBTQ young people, these negative outcomes can be exacerbated by prejudice, fear, and hate experienced in homes, schools, and communities.

We thank the Committee for your ongoing support for suicide prevention and mental health initiatives, and we hope that this letter will identify the critical programs that exist to protect our most vulnerable youth.

The Trevor Project recommends the following FY2015 appropriations to improve access to effective mental health care and reduce suicide risk for young people:

Garrett Lee Smith Memorial Act Suicide Prevention Programs (SAMHSA)

The Garrett Lee Smith Memorial Act provides the largest dedicated source of federal funding for youth suicide prevention efforts, which are a life-saving and effective means to address the daunting issue of youth suicide. We can help avoid tragedy by appropriately funding programs that focus on extreme harming behaviors and mental illness in young people. To date,

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[2] *Suicide in the U.S.: Statistics and Prevention*, NATIONAL INSTITUTE OF MENTAL HEALTH, available at http://www.nimh.nih.gov/health/publications/suicide-in-the-us-statistics-and-prevention/index.shtml#Moscicki-Epi (last visited Mar. 14, 2013).

[3] *2007 National Survey of Children's Health*, DATA RESOURCE CENTER FOR CHILD & ADOLESCENT HEALTH, CHILD AND ADOLESCENT HEALTH MEASUREMENT INITIATIVE, http://www.nschdata.org (last visited May 2009).

[4] Ronald C. Kessler et al., *Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Co-morbidity Survey Replication (NCSR)*, 62 GENERAL PSYCHIATRY 593 (2005); and Philip S. Wang et al., *Failure and Delay in Initial Treatment Contact After First Onset of Mental Disorders in the National Co-morbidity Survey Replication (NCS-R)*, 62 GENERAL PSYCHIATRY 603 (2005).

Garrett Lee Smith funding has supported suicide prevention programs in 49 states, 48 tribes, and 138 colleges. Fully appropriating these programs would ensure that the Suicide Prevention Resource Center continues to provide technical assistance to organizations nationwide; and it would allow for the expansion of state, tribal, and campus grants. Also encompassed within our funding recommendations for these programs is the National Strategy for Suicide Prevention, which works towards a unified approach to suicide prevention through collaboration between public and private sectors; and the National Suicide Prevention Lifeline, which answers more than 94,000 calls a month, including calls from veterans, active duty members and their families, as well as the general public.

Runaway and Homeless Youth Act (Health and Human Services)

An estimated 40 percent of all homeless youth are LGBTQ-identified, often because they are thrown out of their homes or face family rejection.[5] Nearly 2/3 of these young people are likely to attempt suicide at least once.[6]

HUDs last Point in Time Count counted over 46,000 homeless youth, but less than 5,000 beds. Less than ten percent of our homeless youth are receiving services, but funding for the RHYA has not significantly increased since 2008, despite a growing population desperately in need of the services provided by this Act. In order to meet the Administration's goal of ending youth homelessness by 2020, funding for runaway and homeless youth services needs to significantly increase. Through the RHYA, Congress ensures funding for community outreach programs, transitional housing and support services, and counseling and reunification guidance for families to be reconnected. Congress should appropriate $152.5 million to help keep our

[5] Durso, L. E. & Gates, G. J. (2012). *Serving our youth: Findings from a national survey of service providers working with lesbian, gay, bisexual, and transgender youth who are homeless or at risk of becoming homeless*. Los Angeles, CA: The Williams Institute with True Colors Fund and The Palette Fund.
[6] Van Leeuwen, J. M., Boyle, S., Salomonsen-Sautel, S., Baker, D. N., Garcia, J. T., Hoffman, A. & Hopfer, C. J. (2006). Lesbian, gay, bisexual homeless youth: An eight-city public health perspective. *Child Welfare* 85(2), 151-170.

vulnerable youth safe and healthy as part of a nationwide commitment to ending youth homelessness by 2020.

Suicide Prevention Research (SAMHSA)

There is a strong correlation between research funding and morbidity rates associated with diseases and disorders. Between 2009 and 2012, $165 million has been spent on suicide prevention research, and yet in the last decade, suicide rates have increased by 31%. Conversely, over 5 billion dollars has been spent on heart disease research, and rates in the past decade have decreased by 16%.

We encourage you to include an additional $40 million for the National Institute of Mental Health to conduct suicide prevention and brain research, a recommendation that reflects current legislation in the Senate and House (S. 2305/H.R. 7045), the Suicide Prevention Research INnovaTion Act (the SPRINT Act). The SPRINT Act aims to reduce the risk of self-harm, suicide, and interpersonal violence, especially in rural communities with a shortage of mental health services.

Project AWARE – (SAMHSA)

The President's Now is the Time plan is an important step forward to effectively address school safety and youth mental health. These programs must be adequately funded in order to fulfill the promise of making our schools and communities safe for all young people. Through piloting Mental Health First Aid training with $20 million dollars, Project AWARE would support innovative, state-based strategies for improving mental health training and responsiveness to mental health emergencies; and would be particularly effective in rural communities, where community mental health services are less frequently available. Additionally, through $40 million dollars in state grants, Project AWARE would put more trained teachers and mental health professionals on the ground; help school districts make sure students get the referrals they needs; and would underscore the importance of prevention by

offering students mental health services for trauma or anxiety, conflict resolution programs, and other school-based violence prevention strategies.

National Violent Death Reporting System (NVRDS) (CDC)

The NVDRS serves as a clearinghouse for the details and circumstances surrounding suicides completed in the jurisdictions in which it operates. This valuable information informs suicide prevention and crisis intervention efforts, but it is currently only collected in 18 states. Proposals to expand this system have received broad bipartisan support, and the NVDRS expansion was included in the Mental Health Awareness and Improvement Act (S. 689), which passed nearly unanimously in the Senate as an amendment to S. 649. Fully funding the NVDRS with $25 million would allow nationwide collection of this data to further public health research on suicide prevention.

Conclusion

We thank the Committee for taking the time to fully assess our nation's mental health care system, and we appreciate the opportunity to provide a written statement. We strongly support efforts to increase access to suicide prevention and mental health care for young people, and we urge the Committee to fully fund these critical programs.

If you should have any questions regarding this statement, please contact myself or Elliot Kennedy, Government Affairs Counsel, at 202-380-1181 or by email at Elliot.Kennedy@thetrevorproject.org.

Sincerely,

Abbe Land
Executive Director & CEO

Written Testimony of the Coalition of Nutrition Services Agencies (CNSA) for the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies of the Committee on Appropriations for FY 2015

U.S. Senate – Department of Health and Human Services

On behalf of the Coalition of Nutrition Services Agencies (CNSA), I am pleased to submit this testimony to the Members of this Subcommittee on the urgency of increased funding for the domestic HIV/AIDS portfolio in Fiscal Year 2015 (FY15). This funding will be critical to achieving the goals of the National HIV/AIDS Strategy (NHAS). Moreover, increased funding will ensure that the NHAS' vision of the United States in the future as "a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life extending care, free from stigma and discrimination" can become reality.

CNSA supports the domestic HIV/AIDS portfolio funding levels specified in testimonies submitted by the AIDS Budget and Appropriations Coalition and AIDS United.

The Coalition of Nutrition Services Agencies (CNSA) is a national association of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. Collectively, we deliver approximately 10 million meals to PLWHA across the country each year. CNSA is committed to increasing awareness of the essential roles that both food and nutrition services (FNS) and Medical Nutrition Therapy (MNT) play in successfully treating HIV/AIDS, and to expanding access to these critical interventions.

As implementation of the Affordable Care Act (ACA) continues at the federal and state levels, and as challenges to and changes in access to medical care and care completion services for PLWHA multiply, ongoing investment in the Ryan White Program will be essential to ensure that the U.S. can continue to address the disparities that exist at each level of the HIV/AIDS Treatment Cascade. Ongoing investments in the Ryan White Program will also ensure that the successful care delivery infrastructure that has developed through the learned experience and expertise of Ryan White Program providers in finding people living with HIV, linking them to care and ensuring effective treatment will continue to save lives and eventually end the HIV/AIDS epidemic.

Food and nutrition services and medical nutrition therapy provided through the Ryan White Program are crucial to the achievement of an AIDS-Free Generation.

In addition to providing direct medical care, the Ryan White Program also provides important funding for food and nutrition services as part of the holistic model of care that has been the hallmark of the nation's response to HIV/AIDS. The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-

depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian (RD) outside of a primary care visit. FNS encompass home-delivered meals, congregate meals, grocery bags, food pantries and vouchers that complement and are necessary to the fulfillment of MNT.

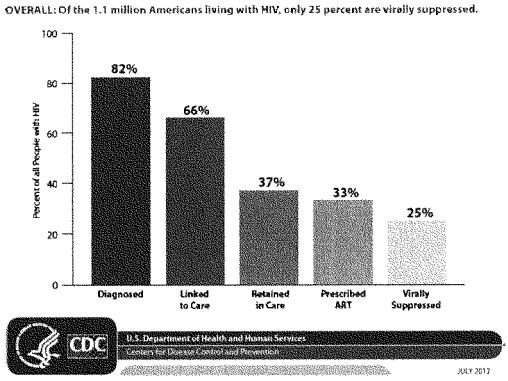
Since 2006, MNT and FNS, provided under the guidance of RDs, have been included as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression. These interventions are also critical to allowing PLWHA to remain in their communities and out of more expensive inpatient medical institutions such as hospitals and nursing homes. Available hospital cost data indicates that the provision of FNS would result in potential savings in the magnitude of billions of dollars for HIV/AIDS alone. They also find that the relatively low cost of FNS programs makes a strong argument for maximal implementation and utilization[i]. In particular:

Access to FNS and MNT for PLWHA is critical to fulfilling the goals of the NHAS

1. **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[ii], thus, FNS is key to prevention[iii].
2. **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[iv].
3. **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[v].

FNS and MNT are essential to addressing each step of the HIV/AIDS Treatment Cascade

The HIV Treatment Cascade is a way to show, in visual form, the proportion of individuals living with HIV/AIDS who are engaged at each stage of HIV care, and to identify issues and opportunities related to improving the delivery of services to PLWHA across the entire continuum of care. FNS adequately addresses medical issues at each of the five stages:



1. **Stage one - only 82% of PLWHA are diagnosed:** FNS is often the gateway to care. People who have access to food are more likely to be in care and thus diagnosed. Preliminary data also appears to show a higher incidence of infection among the food insecure[vi].
2. **State two - only 66% are linked to care**: Access to FNS is often the reason that PLWHA get connected to care, because being active in care is a requirement of receipt of FNS through Ryan White.
3. **Stage three - only 37% are retained in care**: The research above demonstrates that food secure PLWHA are more likely to maintain their care (causation, not correlation).
4. **Stage four - only 33% are prescribed ART:** Food insecurity in PLWHA is independently linked to non-adherence.
5. **Stage five - only 25% are virally suppressed:** Food insecure PLWHA are less likely than food secure PLWHA to have undetectable viral loads (controlled).

The cited research below further demonstrates that access to FNS for PLWHA is good policy along the continuum of care from prevention to treatment, even in environments where people have better access to medical care.

For PLWHA, food insecurity (defined as a PLWHA not having enough money for food that they or their family need; or as sometimes or more often not having enough to eat, or having gone a whole day without anything at all to eat in the past 30 days, or reporting a continuing need for assistance regarding food, groceries or meals) leads to:

- Lower CD4 counts & lower likelihood of having undetectable viral loads[vii]
- More ER visits[viii] & increased morbidity and mortality[ix]
- More missed primary care appointments & reduced use of antiretroviral therapy[x]

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xi].

FNS and MNT are critical interventions that reduce healthcare costs and lead to healthcare savings.

Millions of dollars in healthcare expenditures are saved through the provision of medically tailored meals: One study demonstrated that the six months after initiation of FNS, average monthly health care costs for PLWHA fell from $50,000/month to approximately $17,000/month[xii]. Additionally:

- Access to FNS decreased all clients' (including PLWHA and individuals with other critical and chronic illnesses such as cancer) average monthly healthcare costs, which fell an average of 62% during clients' first three months on the program.
- If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution.

Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[xiii] and the resulting decreases in their healthcare costs. For example, four studies regarding MNT have demonstrated improved outcomes related to energy intake and/or decreased symptoms (with or without oral nutritional supplementation) and cardiovascular risk indices, especially with increased frequency of MNT visits[xiv]. In addition, two studies regarding nutritional counseling (non-MNT) also reported improved outcomes related to weight gain, CD4 count, and quality of life[xv].

The bottom line, MNT and FNS improve health and save healthcare dollars:

- by mitigating the need for expensive home care for individuals whose only need is nutrition, and by complementing and, therefore, reducing home care needs in other situations;
- by decreasing clients' use of emergency room, hospital and nursing home care; and
- through reductions in preventable hospital admissions and readmissions of individuals.

FNS is also a low cost intervention:

- FNS = $20/day vs. hospital stay at $4,000/day
- FNS = $20/day vs. cost of a home health aide at $18/hour
- By preventing one day of hospitalization, you can feed an individual a diet medically-tailored for their unique needs for more than half the year.

In addition, malnutrition is a leading cause of hospitalization in the US for all individuals, with 1 in 3 people in the US admitted to the hospital malnourished[xvi]. Death rates are higher among HIV-infected clients with malnutrition, including those receiving antiretroviral therapies (ARTs)[xvii]. A well-nourished person with HIV who has a controlled viral load is more likely to be able to withstand the effects of HIV infection, supporting immune status and possibly delaying the progression of HIV disease[xviii]. The negative effects of malnutrition are often preventable and are usually not easily reversed. Nutrition-related alterations can occur early in HIV infection; thus, nutrition intervention should begin soon after diagnosis.

Ongoing support and investment in the Ryan White Program is particularly important because FNS, MNT and other crucial care-completion services that depend on this funding

are not included as covered services in the majority of the benefit packages provided by Medicaid and other public insurance initiatives that will be expanded by the ACA.

Without the Ryan White Program and its financial support of care completion services, the achievements we have made in addressing the Treatment Cascade will be lost. FNS and other care completion services are essential throughout the life of a client to ensure that medical care and treatment will be successful. It is critical to both individual client and public health that we keep the Ryan White FNS Program strong. Without the Ryan White Program, these and many other vital services will no longer be available to the millions of PLWHA who desperately depend on them to stay alive. Losing these services will result in the deterioration of individual and public health and ultimately roll back the tide on the critical advances this nation has made in transforming HIV/AIDS from a death sentence to a chronic illness, taking us even further away from the goal of an AIDS Free Generation.

CNSA is deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS and MNT, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate MNT and FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

CNSA appreciates the opportunity to offer testimony regarding the FY 2015 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library. **On behalf of our members and partners, I urge the Subcommittee to consider and support the FY2015 funding levels that have been outlined by the AIDS Budget and Appropriations Coalition and AIDS United.**

Thank you.

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DISABILITY AND REHABILITATION
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Testimony Submitted for the Written Record

by the

Disability and Rehabilitation Research Coalition

Before the

Subcommittee on Appropriations for the Departments of Labor, Health and Human Services, Education, and Related Agencies

United Stated House of Representatives

On the

Future of Biomedical Research

March 26, 2014

Submitted by Peter W. Thomas, J.D.
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Chairman Kingston, Ranking Member DeLauro, and Members of the Subcommittee:

On behalf of 30 national organizations that comprise the Disability and Rehabilitation Research Coalition ("DRRC"), thank you for the opportunity to submit this testimony for the record on the Future of Biomedical Research. My name is Peter Thomas and I am counsel to the DRRC. I have personally experienced the benefits of rehabilitation and disability research throughout the course of my life as a bilateral leg amputee since the age of ten. The advancements in prosthetics alone over the past 40 years have been remarkable and many other areas of rehabilitation science have experienced the same progress. The National Institutes of Health supports approximately $300 million of rehabilitation research each year, with the "home" of rehabilitation science located at the National Center for Medical Rehabilitation Research ("NCMRR") within the Eunice Kennedy Shriver National Institute for Child Health and Human Development ("NICHD").

NCMRR was created by statute in 1990 after Congress debated whether to create an independent rehabilitation research Institute at NIH. Instead, a center was created and housed within NICHD under the theory that this Institute could nurture the center as it developed. For the first ten years of its existence, this concept proved successful. A comprehensive rehabilitation research plan was developed and published in 1993 and the budget grew with significant increases in funding throughout the 1990's and during the period of NIH's doubling of funding. Early investments in training grants have developed a significant cadre of senior rehabilitation researchers, and a diverse portfolio of research grants has been funded.

Rehabilitation and disability research is cross-cutting, multi-disciplinary, and focuses on restoring and improving functional capacity in individuals who have experienced an illness, injury, disability or chronic condition. This type of research also focuses on maintaining and

preventing deterioration of functional skills and abilities in order to enhance quality of life and independent living. This is the kind of research that matters most to individuals when "cure" is no longer an option. Rehabilitation research crosses the lifespan and clinically focused research can rapidly translate into direct patient care in order to achieve maximal health care outcomes. Given the prevalence of disability in this country (approximately 13 to 14 percent) and the strong correlation between disability and aging, greater investments in rehabilitation science have huge potential to guide better, more effective health and rehabilitative care in the future, and make the most of precious health care resources.

Rehabilitation research involves both basic and clinical science. To illustrate its value, consider the following research topics and the implications for people with these conditions:

- A variable geometry prosthetic socket that changes shape with the natural, volumetric changes in the residual limb during the course of a day's use of a prosthetic limb. This ensures proper fit and function of the prosthetic limb and decreases the risk of skin breakdowns and other secondary conditions.
- Seating systems that allow non-ambulatory individuals to rely on mobility devices (i.e., wheelchairs) to function throughout the day without developing decubitus ulcers or spinal mal-alignment due to long term wheelchair use.
- Determining the types and amounts of rehabilitation therapies and cognitive interventions needed to optimize recovery and rehabilitation in people with brain injuries due to trauma, stroke and other causes.
- Regeneration of nerve activity and function in people with spinal cord injury and other neuromuscular disorders.

- Sensory feedback technology that allows people with peripheral vascular disease and diabetes to better "feel" their insensate lower limbs to prevent ulcerations that often lead to amputation.

In recent years, the rehabilitation research program at NIH plateaued and has not thrived. As a result, Dr. Collins, NIH Director, and Dr. Alan Guttmacher, NICHD Director, empanelled a Blue Ribbon Panel on Medical Rehabilitation Research at the NIH ("BRP"). The panel produced a report and recommendations in December 2012 to the NICHD Director. Among the recommendations was a need to elevate the stature of rehabilitation research at NIH, greater coordination of rehabilitation science across NIH's Institutes and Centers ("ICs"), and a dedicated budget for NCMRR. In fact, in addition to a number of functional improvements to the NIH's rehabilitation research program, the BRP report recommended that NCMRR transition to an independent Institute or Center reporting directly to the NIH Director, or a new Office in the Office of the NIH Director. This was intended to elevate the stature and importance of rehabilitation science as a priority area of NIH research and lead to greater coordination of rehabilitation research being pursued by multiple ICs.

The NIH has responded to date by dedicating a definable portion of the NICHD extramural research budget to NCMRR research. This has created a stable floor of NCMRR research funding that we hope will grow in future years. New leadership for the Center is underway as a search committee seeks a new Director to lead the Center. And the rehabilitation research plan that was published in 1993 is expected to be updated in the near future to address current gaps in rehabilitation science and address contemporary priorities in the field. These are very positive developments that the DRRC supports. However, there are two major issues of concern that remain unresolved.

1. Co-Funding of Rehabilitation Research: DRRC believes, and NIH recognizes, that coordination in rehabilitation science across the NIH Institutes and Centers is in need of significant attention. NIH has chosen to address this concern of the Blue Ribbon Panel through a co-funding model that seeks to transition NCMRR into a co-funder of rehabilitation research grants that are primarily housed in other ICs, with these other ICs taking the lead in selection and management of these grants. This differs markedly from the way NCMRR currently operates and, arguably, alters NCMRR's statutory mission of "conducting and supporting" rehabilitation research. While NIH's intention is to permit NCMRR to continue to fund completely on its own a small number of high priority grants, the majority of the research portfolio will be directed outside of NCMRR in other NIH ICs. NIH argues that this will stimulate investment by other ICs in rehabilitation science and lead to greater coordination of rehabilitation research. But there is a significant risk that this co-funding model will lead to a dilution of priority items on the rehabilitation research agenda and undermine NCMRR as the "home" for rehabilitation science at NIH. There is also a risk of diluting the intellectual capacity currently residing in NCMRR staff to continue to assist rehabilitation scientists through the application and implementation of rehabilitation research grants. DRRC, therefore, requests Congress to examine this issue and work with NIH officials and DRRC organizations to minimize the risks described above and establish benchmarks to measure success or failure of this co-funding model as it is being implemented.
2. Elevation in the Stature of Rehabilitation Science at NIH: The only major recommendation of the Blue Ribbon Panel report to remain unaddressed by NIH is the structural recommendation to elevate the NCMRR to an independent Institute or Center reporting

directly to the NIH Director, or to establish a new Office of Rehabilitation Research within the Office of the NIH Director. Implementation of this structural recommendation would require a statutory change and the NIH did not materially address this major recommendation in its responses to the BRP report. Elevation of NCMRR has been viewed from the start as a critical step in achieving sufficient critical mass to coordinate rehabilitation science across all the ICs at NIH that conduct and support research directly addressing—or related to—rehabilitation science. While NICHD has nurtured the Center in its first two decades of existence, the NCMRR's current placement, a Center within the Child Health Institute, does not easily allow for successful implementation of a coordinating committee that—by statute—the NCMRR Director chairs. In addition, its location within NIH does not result in sufficient focus and priority among the ICs conducting rehabilitation research that benefits people with myriad conditions and disabilities across the lifespan. This is why it is so important for NIH to materially address this recommendation of the Blue Ribbon Panel and offer guidance to Congress as to how NIH would implement it in the most appropriate manner possible, whether or not the recommendation is adopted at this time.

Rehabilitation and disability research offers such incredible promise for improving the lives of people with injuries, illnesses, disabilities and chronic conditions. It stands to dramatically improve our health care delivery system while targeting precious health care resources where they can make the greatest impact. DRRC strongly urges Congress to further explore the recommendations of the Blue Ribbon Panel on Medical Rehabilitation Research and work with NIH officials and DRRC organizations to maximize the federal investment in this important research area of priority.

Thank you for the opportunity to submit this statement for the written record.

DRRC Member Organizations

American Academy of Neurology
American Academy of Orthotists & Prosthetists
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association of Spinal Cord Injury Psychologists and Social Workers
American Association on Health and Disability
American Congress of Rehabilitation Medicine
American Hospital Association
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Amputee Coalition of America
Arthritis Foundation
Association of Academic Physiatrists
Association of Rehabilitation Nurses
Brain Injury Association of America
Child Neurology Foundation
Child Neurology Society
Christopher and Dana Reeve Foundation
Disability Rights Education and Defense Fund
Federation for American Hospitals
March of Dimes
National Association for the Advancement Orthotics & Prosthetics
National Association of Rehabilitation Research Training Centers
National Association of State Head Injury Administrators
National Association of Veterans' Research and Education Foundations
National Council on Independent Living
National Multiple Sclerosis Society
North American Brain Injury Society
Paralyzed Veterans of America
RESNA
United Spinal Association

Testimony of Joseph Rodrigues
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Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – Public Witness Hearing March 25, 2014

The National Association of State Long-Term Care Ombudsman Programs (NASOP) is pleased to submit this statement for the record and the following funding recommendations for Fiscal Year 2015 for the Long-Term Care Ombudsman Programs administered through the Administration for Community Living (ACL).

- $5 million authorized under the Elder Justice Act for Long-Term Care Ombudsman Program (LTCOP) services and training to fight elder abuse, neglect, and exploitation;
- $16.83 million authorized under Title VII of the Older Americans Act for LTCOPs to restore funding back to the FY 2011 level;
- $20 million for LTCOP services in assisted living facilities; and
- $1 million authorized under Title II of the Older Americans Act for the National Long-Term Care Ombudsman Resource Center (NORC).

NASOP, formed in 1985 as a non-profit organization, is composed of state long-term care ombudsmen representing their state programs created by the Older Americans Act (OAA). The primary function of the LTCOP in the federal OAA is to identify, investigate, and resolve complaints that relate to action, inaction or decisions that may adversely affect the health, safety, welfare, and rights of residents of long-term care facilities. Ombudsman representatives work with the consent and at the direction of residents in the resolution of their problems. They visit

residents living in nursing homes and residential care homes. Ombudsman representatives ask them about problems or concerns they have and if they need or want our help to resolve these issues. Ombudsman representatives act as their advocates. We strongly believe that our work not only improves the quality of life for millions of long-term care facility residents, but also saves Medicare and Medicaid resources by avoiding unnecessary costs associated with poor quality care.

In federal Fiscal Year 2012, over 11,000 volunteers, including 8,712 individuals certified to investigate complaints, and 1,180 staff served in 573 local LTCOPs. Ombudsmen investigated and worked to resolve 193,650 complaints made by 126,398 individuals. Ombudsmen were able to resolve or partially resolve 73%, or almost three out of every four complaints investigated. In addition, ombudsmen provided information on rights, care and related services 405,589 times.

NASOP understands that this Subcommittee faces a strained financial situation, but a continued commitment to Ombudsman programs advocating for the health care needs and safety of millions of older adults living in nursing homes and assisted living facilities across the nation should remain a high priority. Since 1978, the LTCOP has been a core program of the OAA. It is the only program in the OAA that specifically serves residents of nursing homes and assisted living facilities. We all appreciate and value the importance of living in one's own home. The OAA provides critically needed home and community based services that often delay institutionalization. However, some elders can no longer live safely in their own homes and must move at some point in their lives to either an assisted living facility or a nursing home. These residents are usually frail and extremely vulnerable and rely on the advocacy services of the LTCOP.

Demand for our services and advocacy is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. In addition, there continues to be a disturbing increase in the frequency and severity of citations for egregious regulatory violations by long-term care providers. These violations put facility residents in immediate jeopardy of harm. This trend suggests a frightening decline in the quality of long-term care services. Ombudsmen are needed now more than ever in nursing homes, board and care facilities, and in assisted living communities. As well, the demand placed on the program by the need to assist residents who are relocating from long-term care facilities that are downsizing or closing their doors continues to complicate ombudsman programs' daily operations.

Administrators in many long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation and this form of outreach has also placed an increasing strain on available advocacy resources. In order to improve advocacy and services available to residents of long-term care facilities, NASOP recommends several augmentations to appropriations that support the work of LTCOP.

NASOP requests $5 million to **support the work of the LTCOP under the Elder Justice Act**. This appropriation would allow states to hire additional staff and leverage that staff to recruit additional volunteers to help support the investigation of complaints of abuse, neglect, and exploitation of residents of nursing home and assisted living facilities.

NASOP request $16.83 million authorized under Title VII of the Older Americans Act for LTCOPs **to restore funding back to the FY 2011 level**. Programs in every district and state are

suffering from recent cuts. These funds would help in a partial way to restore our reduced ability to visit residents in nursing homes.

NASOP requests $20 million to **support 333 additional Ombudsman** salaried staff at an estimated $60,000 average annual salary/fringe benefits and necessary staff training. The requests adds new ombudsman positions specifically dedicated to providing Ombudsman services to residents of assisted living facilities and other community-based long- term care delivery systems, which currently suffer from a significant lack of personnel resources around the country.

Finally, NASOP wants to acknowledge the importance and value of the **National Long- Term Care Ombudsman Resource Center** (NORC). The NORC provides valuable and reliable technical assistance, training, and support to state and local LTCOPs.

NASOP requests an appropriation of $1 million to support the work of the NORC in providing training and technical assistance to state and local LTCOPs. Congress funds the NORC at $550,000 per year; the very same level of funding it has received since 1993. This request adds $450,000 to the line item for the NORC, which is such a critical component of the ombudsman program. The NORC plays an integral role in assuring the overall effectiveness of LTCOPs across the country through its training, educational materials, data analysis, and best practices efforts.

Overall, Ombudsmen offer valuable consumer protections to residents and provide a voice for those unable to speak for themselves. Every day in America, 10,000 more persons reach the age of 65 years. With a rapidly growing older population, LTCOPs can continue to enhance the

quality of life, improve the level of care, protect the individual's rights and promote the dignity of Americans across the nation.

On behalf of NASOP, thank you for this opportunity to share our requests for support of this important program that protects the health, safety, welfare, and rights of vulnerable older adults and persons with disabilities. We ask that you thoughtfully consider our detailed request for funding in FY 2015.

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American Society of Plant Biologists

Cultivating a better future through plant biology research

Official Written Testimony in Support of the National Institutes of Health's

Fiscal Year 2015 Budget

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

Committee on Appropriations

U.S. House of Representatives

March 20, 2014

On behalf of the American Society of Plant Biologists (ASPB), we would like to thank the Subcommittee for its support of the National Institutes of Health (NIH). ASPB and its members strongly believe that sustained investments in scientific research will be a critical step toward economic recovery and job creation in our nation. ***ASPB supports the maximum fiscal year 2015 appropriation for NIH and asks that the Subcommittee Members encourage increased support for plant-related research within the agency;*** 25% of our medicines originate from discoveries related to plant natural products, and such research has contributed in innumerable ways to improving the lives and health of Americans and people throughout the world.

ASPB is an organization of some 4,500 professional plant biology researchers, educators, students, and postdoctoral scientists with members across the nation and throughout the world. A strong voice for the global plant science community, our mission—achieved through work in

the realms of research, education, and public policy—is to promote the growth and development of plant biology, to encourage and communicate research in plant biology, and to promote the interests and growth of plant scientists in general.

Plant Biology Research and America's Future

Among many other functions, plants form much of the base of the food chain upon which all life depends. Importantly, plant research is also helping make many fundamental contributions in the area of human health, including that of a sustainable supply and discovery of plant-derived pharmaceuticals, nutriceuticals, and alternative medicines. Plant research also contributes to the continued, sustainable, development of better and more nutritious foods and the understanding of basic biological principles that underpin improvements in the health and nutrition of all Americans.

Plant Biology and the National Institutes of Health

Plant science and many of our ASPB member research activities have enormous positive impacts on the NIH mission 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." In general, plant research aims to improve the overall human condition—be it food, nutrition, medicine or agriculture—and the benefits of plant science research readily extend across disciplines. In fact, 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 maintenance requirements that are less expensive than those required for the use of animal systems.

Many fundamental biological components and mechanisms (e.g., cell division, viral and bacterial invasion, polar growth, DNA methylation and repair, innate immunity signaling and circadian rhythms) are shared by both plants and animals. For example, a process known as RNA interference, which has potential application in the treatment of human disease, was first discovered in plants. Subsequent research eventually led to two American scientists, Andrew Fire and Craig Mello, earning the 2006 Nobel Prize in Physiology or Medicine. More recently scientists engineered a class of proteins called TALENs capable of precisely editing genomes to potentially correct mutations that lead to disease. That these therapeutic proteins are derived from others initially discovered in a plant pathogen exemplifies the application of plant biology research to improving human health. These important discoveries again reflect the fact that some of the most important biological discoveries applicable to human physiology and medicine can find their origins in plant-related research endeavors.

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." Without good nutrition, there cannot be good health. Indeed, a World Health Organization study on childhood nutrition in developing countries concluded that over 50% of child deaths under the age of five could be attributed to malnutrition's effects in weakening the immune system and exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition, but chronic nutritional deficiencies brought about by overreliance on single crops for primary staples. Plant researchers are working today to address the root cause of this problem by balancing the nutritional content of major crop plants to provide the full range of essential micronutrients in plant-based diets.

By contrast to developing countries, obesity, cardiac disease, and cancer take a striking toll in the developed world. Research to improve and optimize concentrations of plant compounds known to have, for example, anti-carcinogenic properties, will hopefully help in reducing disease incidence rates. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists can and are making toward realizing the long-awaited goal of personalized medicine, especially for preventative medicine.

Drug Discovery – Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, 60% of anti-cancer drugs in use within the last decade are of natural product origin—plants being a significant source. An excellent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol, which was discovered as an anti-carcinogenic compound from the bark of the Pacific yew tree through collaborative work involving scientists at the NIH National Cancer Institute and plant natural product chemists. Taxol is just one example of the many plant compounds that will continue to provide a fruitful source of new drug leads.

While the pharmaceutical industry has largely neglected natural products-based drug discovery in recent years, research support from NIH offers yet another paradigm. Multidisciplinary teams of plant biologists, bioinformaticians, and synthetic biologists are being assembled to develop new tools and methods for natural products discovery and creation of new pharmaceuticals. We appreciate NIH's current investment into understanding the biosynthesis of natural products through transcriptomics and metabolomics of medicinal plants. The recently released "Genomes to Natural Products" funding opportunity is also to be applauded as a potential avenue for new plant-related medicinal research, and we strongly encourage the continuation of these types of

investments and other plant-related initiatives which can help further achievement of the NIH mission.

Conclusion

Although NIH does recognize that plants serve many important roles, the boundaries of plant-related research are expansive and integrate seamlessly and synergistically with many different disciplines that are also highly relevant to NIH. As such, ***ASPB asks the Subcommittee to provide the maximum appropriation and direction to NIH to support additional plant research in order to continue to pioneer new discoveries and new methods with applicability and relevance in biomedical research.***

Thank you for your consideration of ASPB's testimony. For more information about ASPB, please see www.aspb.org.

Testimony Submitted to the House Appropriations Subcommittee on

Labor, Health and Human Services, Education

William L. Dewey, Ph.D., President,

Friends of the National Institute on Drug Abuse

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 (NIDA). The Friends of the National Institute on Drug Abuse 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 through 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. Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least $32 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2015 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

Marijuana Research. *Efforts to legalize or "medicalize" marijuana continue across the United States. The Committee understands that research from different areas of science is converging on the fact that regular marijuana use by young people can have a long-lasting negative impact on the structure and function of their brains, resulting in lower educational achievement, reduced IQ, etc. Research clearly demonstrates that marijuana has the potential to cause problems in daily life or make a person's existing problems worse. NIDA is encouraged to*

continue to fund research on preventing and treating marijuana abuse and addiction, and the possible health and policy implications of proposals to implement "medical marijuana" or marijuana legalization programs across the U.S.

Opiate Abuse and Addiction. *The Committee is concerned about the continued crisis of prescription drug abuse in the U.S. In particular, the June 2011 IOM report on pain indicates that abuse and misuse of prescription opioid drugs resulted in an annual estimated cost to the nation of $72,500,000,000. Further, the Committee is very concerned with the potential rise in heroin abuse and addiction as a result of successful efforts to combat the prescription drug side of this issue. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of pain medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research into such medications; and 3) report on what we know regarding the transition from opiate analgesics to heroin abuse and addiction within affected populations.*

Medications Development. *The Committee recognizes that next-generation pharmaceuticals will surely take advantage of new technologies. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this active area of research is the development of safe and effective vaccines or antibodies that target specific drugs, like nicotine, cocaine, and heroin, or drug combinations. The Committee is excited by this approach - if successful, immunotherapies, alone or in combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and, maybe even someday, prevent addiction. The Committee looks forward to hearing more about work in this area.*

Nurturing Talent and Innovation in Research. *The Committee commends NIDA for its continued support of innovative research on drug addiction and related health problems such as pain and HIV/AIDS, and the Institute's effort to be at the forefront of training the next generation of innovative researchers. The 6 year-old Avant-Garde award is a good example of a program that stimulates high-impact research that could lead to groundbreaking opportunities for the prevention and treatment of HIV/AIDS in drug abusers. The Committee understands that NIDA is now crafting a new kind of award, which would blend NIH's Pioneer and New Innovator award mechanisms. This new opportunity, called "AVENIR" awards, is designed to attract creative young investigators into HIV/drug abuse public health research. The Committee strongly supports this effort, and asks the Institute to report on its progress in future appropriations and related requests.*

Research to Assist Military Personnel, Veterans, and Their Families. *The Committee recognizes the significant health challenges, including substance abuse and addiction, faced by military personnel, veterans, and their families. Many of these individuals need help confronting war-related problems including traumatic brain injury, PTSD, depression, anxiety, sleep disturbances, and substance abuse and addiction. The Committee commends NIDA for its successful efforts to coordinate and support research with the Department of Veterans Affairs, Department of Defense, and other NIH Institutes focusing on these populations, and strongly urges NIDA to continue work in this area.*

Raising Awareness and Engaging the Medical Community in Drug Abuse and 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 urges the Institute to continue its focus on activities to provide physicians and*

other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.

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 morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease –this new knowledge has helped to correctly situate drug 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, scholars supported by NIDA continue to advance 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 medications development and 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 include the recent increase in lethalities due to heroine, as well as the continued abuse of prescription opioids and the recent increase in designer drugs availability and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the FY2015 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, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

FY 2014 HOUSE APPROPRIATIONS COMMITTEE PUBLIC TESTIMONY
WRITTEN TESTIMONY OF
MARGARET ANDERSON
EXECUTIVE DIRECTOR, *FASTERCURES, A CENTER OF THE MILKEN INSTITUTE*
FOR THE SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

March 28, 2014

Chairman Kingston, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to present my testimony urging the subcommittee to reaffirm our nation's commitment to medical research by investing at least $32 billion in funding for the National Institutes of Health (NIH) in FY 2015.

I am Margaret Anderson, executive director of *FasterCures*, a center of the Milken Institute. *FasterCures* is a nonprofit and nonpartisan organization focused on improving the medical research and development system so that we can speed up the time it takes to get important new medicines from discovery to patients. We work across diseases, disciplines, and sectors – academic institutions, government agencies, biotechnology and pharmaceutical companies, investors, medical research foundations, philanthropic organizations, and patient advocacy groups – to identify and eliminate roadblocks slowing down medical progress. We strongly believe that for the medical research system to work effectively, we need the NIH to be able to function at peak performance so it can continue to support groundbreaking programs and pursue transformative, life-saving discoveries.

Investment in NIH Research Saves Lives

The past few decades have brought enormous breakthroughs in the fundamental knowledge necessary to understand, prevent, diagnose, and treat many diseases. Federal investment in research since the 1970s has helped double survival rates for multiple cancers. Consider the $7 a year per American investment to support HIV/AIDS research and how that has turned a life-threatening disease into a manageable condition, when access to therapies is assured. Breakthroughs in HIV/AIDS research enabled by the NIH have saved us over $1.4 trillion[i] and, just earlier this month, we heard about the second baby born with HIV that has shown no signs of the virus after being treated with antiretroviral drugs.[ii] Meanwhile, NIH-driven cardiovascular research has led to treatments that saved more than a million American lives. But, there remains a formidable list of diseases that do not have therapeutic options.

One in three Americans suffer from cancer, Alzheimer's disease, diabetes, Parkinson's disease, heart disease, and other illnesses for which there are still no cures—and, in many cases, few meaningful treatment options. That's a lot of us, and we all need an NIH that is able to deliver high quality research that could yield life-saving medical advances.

NIH Yields Enormous Returns to the Economy

NIH-driven research saves lives, and is also a boon to the economy. In 2011, NIH investment supported 432,000 jobs and generated $62.13 billion in economic activity.[iii]

Choose any medical advance announced by a pharmaceutical or biotechnology company, and chances are the basic science on which it was built emerged from an NIH-funded lab – 74% of pharmaceutical and biotechnology companies having licensed patents from NIH-funded academic research.[iv] Consider a Wisconsin-based, multibillion dollar life science

company known as TomoTherapy. Largely supported by NIH grants, a group of researchers at University of Washington developed a machine to improve the accuracy of cancer treatment by reducing the ability for radiation to damage non-cancerous organs near the area of treatment. Within 10 years of treating its first patient, TomoTherapy evolved into a major private sector company, employing more than 1,100 people worldwide, and its fiscal year 2012 revenue exceeding $400 million.[v]

Beyond job-creation, we've all seen how effective therapies yield highly productive employees. Thanks in large part to NIH research, Americans are living nearly 30 years longer than they did in 1900[vi]. Not only have these gains in longevity enriched many lives, they have added an estimated $3.2 trillion annually to the U.S. economy since 1970.[vii]

These numbers provide us with a strong argument for investing in the NIH. Scaling back now has major repercussions. Consider our aging population: demographers, epidemiologists, and economists project that the rising costs of age-related chronic conditions will surpass our ability to pay for care, leaving us with bleak choices between widespread suffering and financial ruin. Every year, American taxpayers spend $203 billion on Medicare and Medicaid expenses related to Alzheimer's disease alone. If substantial progress is not made in stopping Alzheimer's through effective prevention and treatment options, Medicare and Medicaid spending will reach $1.1 trillion in today's dollars by 2050 if we don't change its course. And Alzheimer's is just one of many examples.[viii]

NIH Research Positions U.S. Leadership in Innovation

At a time of unprecedented scientific opportunity, forward-thinking investments in our biomedical research infrastructure not only saves lives and creates jobs, it also reinforces the U.S. as the global leader in innovation.

For more than a decade now, NIH funding has been steadily weakening.[ix] China, India, Japan, the U.K., Singapore, and other nations are catching up quickly as they increase research budgets as much as 30% a year[x], while the NIH budget has lost nearly 20% of its purchasing power since 2003. China alone has pledged to devote $308.5 billion just to biotechnology between 2012 and 2017, compared with a projected $160 billion for all NIH programs.[xi]

We Cannot Squander the Promise of Science

In an opinion piece in the Baltimore Sun, *FasterCures* chairman Michael Milken and former NIH Director Elias Zerhouni wrote that "it makes no sense to eat our seed corn with across-the-board cuts that don't distinguish between programs that can safely be eliminated and those that produce high returns."[xii]

At *FasterCures*, we're buoyed by the enthusiasm we see in young scientists who have just received their first grants and the biomedical research entrepreneurs whose ideas are turning into thriving companies. We are energized by the novel solutions driven by patient organizations. We have seen the potential for personalized medicine to deliver high quality, cost-effective care. But, we also know that these pockets of transformative innovation will not, *cannot*, be scaled without a strong NIH.

In Summary

The decisions we make today will have implications long into the future. Now is the time to lean in and ensure everyone understands the NIH's value proposition and relevance to

patients and the economy, because it already takes too long to get from an idea to a treatment. In the U.S., every 68 seconds, someone develops Alzheimer's disease. Every 24 seconds, someone is diagnosed with cancer. Every 18 seconds, someone is diagnosed with diabetes. Patients' lives are literally on the line. Time equals lives, so goes our mantra at *FasterCures*. We cannot let the possibility of a cure sit in a cupboard instead of pursuing its full potential to benefit patients, families, and communities.

We understand the nation's long-term fiscal challenges and recognize that overall spending must be sustainable. Precisely because of these pressures, not in spite of them, we should invest in the NIH and make it a national priority.

Thank you again, distinguished Committee members, for your service to our nation. I appreciate the opportunity to present this written testimony. I would be happy to answer any questions you have or provide additional information.

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Outside Witness Testimony

From the American Psychological Association

Re Fiscal Year 2015 Appropriations for

Labor, Health and Human Services and Education

March 28, 2014

The American Psychological Association (APA) is the largest scientific and professional organization representing psychology in the US: its membership includes nearly 130,000 researchers, educators, clinicians, consultants and students. APA works to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives. Many programs in the Labor-HHS-Education bill impact science, education, and the populations served by clinical psychologists.

National Institutes of Health --The Consolidated Appropriations Act of 2014 increase for NIH did not give back all of the funds cut by sequestration in FY 2013 nor did it restore the purchasing power lost over the past decade. As a member of the Ad Hoc Group for Medical Research, APA recommends that NIH receive at least $32 billion in FY 2015 as the next step toward a multi-year increase in our nation's investment in health research. APA also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to health research that squander invaluable scientific opportunities, discourage young scientists, threaten or slow improvements in our nation's health, and jeopardize our economic future.

Psychological scientists are supported by research grants or training programs in almost all of NIH's 27 institutes and centers. They are working with animal models or human participants to improve diagnosis and treatment of Alzheimer's disease and autism, to understand the mechanisms underlying adoption of healthy behaviors, and to help prevent transmission of HIV and unhealthy behaviors such as substance abuse. Behavioral research is critical to NIH's mission: approximately 40 percent of premature mortality

in the U.S. is due to behaviors such as smoking, sedentary lifestyle, and alcohol and other drug consumption. APA encourages continued support for OppNet, the trans-institute initiative funded through the Office of Behavioral and Social Sciences Research that has led to some $90 million in funding of basic research through FY 2013 on critical issues such as sleep, stress, and multisensory perception. As NICHD develops initiatives to understand and prevent harmful and costly preterm births, APA encourages that institute to enhance research on psychological factors that may contribute.

Centers for Disease Control and Prevention-- As a member of the CDC Coalition, APA supports at least $7.8 billion for core programs in FY 2015. Rather than relying on the Prevention Fund and other transfers, APA urges the committee to restore CDC's budget authority. As a member of the Friends of NCHS, APA recommends a program level of $182 million for the center. APA strongly supports the President's request for increased funding for the National Injury Prevention and Control Center, including $10 million for gun violence prevention research, to allow the CDC to carry out the critical research agenda developed last year by the Institute of Medicine and the National Research Council, and for $23.57 million for the National Violent Death Reporting System, to allow for its expansion to all 50 states and DC. APA is pleased that the Committee provided an increase in funding for the Prevention Research Centers program in FY 2014, and urges that funding be restored for the program to at least $28 million in FY 2015, consistent with the FY 2011 funding level, to support research essential to the focus on prevention. APA supports the President's request of $360.7 million for surveillance, research and programs to support HIV prevention in the Division of HIV/AIDS Prevention, an increase of $4.3 million above FY 2014. Additional resources should be directed toward behavioral and social science research that optimizes outcomes along the HIV care continuum; implementation science to enhance linkage and retention in care; research on adherence to treatment; developing and scaling up interventions for most the impacted persons living with HIV/AIDS; development, adaptation and

implementation of innovative strategies to address stigma and discrimination; and research into structural and environmental factors that drive the HIV epidemic.

Substance Abuse and Mental Health Services Administration-- APA strongly supports:

- The National Child Traumatic Stress Network (NCTSN) program. APA recommends increased support for the Network's efforts on behalf of the recovery of children, families, and communities affected by physical and sexual abuse, school and community violence, natural disasters, sudden death of a loved one, war's impact on military families, and other trauma.
- Garrett Lee Smith Memorial Act programs--Campus Suicide Prevention, State and Tribal Youth Suicide Prevention and the Suicide Prevention Resource Center. These effective national programs help meet the mental and behavioral health needs of youth and young adults through access to prevention, education, and outreach services to reduce suicide risk in these populations. First authorized in 2004, the Garrett Lee Smith Memorial Act has supported youth suicide prevention grants in 49 States, 48 Tribes or Tribal organizations, and 138 institutions of higher education.
- Minority Fellowship Program. APA remains concerned that while minorities represent 30% of the population and are projected to increase to 40% by 2025, only 23% of recent doctorates in psychology, social work and nursing were awarded to minorities. We encourage the Committee to support the Administration's $5 million increase for the MFP as requested in the FY 2015 budget proposal. The increase reflects the need to continually grow the pool of culturally competent mental health professionals.
- Mental Health Care Provider Education in HIV/AIDS Program, in CMHS. Continuing education for mental health providers in these crucial clinical issues remains a high priority. APA urges Congress to maintain level funding in CMHS for the training of psychologists, social workers, and psychiatrists in mental health and psychosocial issues related to HIV/AIDS.

- SAMHSA-funded programs providing vital substance abuse and mental health services to people with HIV/AIDS.
- SAMHSA's Safe Schools/Healthy Students program that expands aecess to mental and behavioral health services in schools and reduces violence through prevention and early intervention supports.

Health Resources and Services Administration -- APA recommends funding SSA Section 512 regarding services to individuals with a postpartum condition. Postpartum Depression (PPD) is one of the most common and frequently undiagnosed conditions associated with childbirth. In the U.S. approximately one in five women suffers from PPD each year. While PPD is a widespread problem, under the current USPSTF guidelines, depression screening is available as an Essential Health Benefit to all non-pregnant adults, yet excludes the vulnerable population of pregnant women. APA supports funding for PPD research and treatment under Section 512 of the Social Security Act, to incorporate screening and linkages to behavioral health treatment for women suffering from this condition. APA encourages the Committee to support incorporation of PPD screening into the SSA Title V programs administered by HRSA as well as Healthy Start. APA also encourages the Committee to urge the Secretary to prioritize the issue of PPD by raising awareness, expanding research, and establishing grants for the operation and coordination of cost-effective services to afflicted women and their families. APA recommends continued investments in the mental and behavioral health workforce, including $6.9 million for the Graduate Psychology Education program to increase the number of health service psychologists trained to provide services to high-need and high-demand underserved populations in both urban and rural communities. This program supports the training of doctoral psychology students, interns and postdoctoral residents with other health professionals while they provide supervised mental and behavioral health services to underserved and vulnerable populations, including: children, older adults, veterans and their families, individuals with chronic illnesses, and victims of abuse and trauma.

In 2010-2011 alone, the GPE program supported the training of 620 graduate psychology students and provided mental and behavioral health services to over 46,000 underserved persons. APA encourages HRSA to maintain a strong emphasis on serving rural veteran populations and their families. There is a growing need for highly trained mental and behavioral health professionals to deliver evidence-based services to the rapidly aging population. APA encourages HRSA to reinstate the geropsychology component, and help integrate health service psychology trainees at Federally Qualified Health Centers.

HHS programs on aging: Given that approximately 20-25% of older adults have a mental or behavioral health problem, and older white males (age 85 and over) currently have the highest rates of suicide of any group in the U.S. APA supports an expanded effort to address the mental and behavioral health needs of older adults including implementation of the mental and behavioral health provisions in the *Older Americans Act Amendments of 2006,* grants to States for the delivery of mental health screening, and treatment services for older individuals and programs to increase public awareness and reduce the stigma associated with mental disorders in older individuals.

APA also recommends continued support of the HHS's Lifespan Respite Program. Respite care can provide family caregivers with relief necessary to maintain their own health, bolster family stability and well-being, and avoid or delay more costly nursing home or foster care placements.

Department of Education -- APA supports strengthening our federal investment in gifted and talented education and encourages Congress to fund the Javits Gifted and Talented Education Program in FY 2015, funded last year at $5 million. And, as a member of the Friends of the Institute of Education Sciences (IES), APA supports $202.3 million for IES's research, development and dissemination portfolio, consistent with the Administration's 2013 and 2014 requests. This would support critical investments to provide evidence-based information on effective educational practices to parents, teachers and schools, and new research to fill gaps in knowledge.

Spina Bifida Association
Written Testimony to the House LHHS Appropriations Subcommittee
Regarding Fiscal Year 2015 Spina Bifida Related Funding
Ana Ximenes, SBA Chairman
March 28, 2014

Background and Overview

On behalf of the estimated 166,000 individuals and their families who are affected by all forms of Spina Bifida — Spina Bifida Association (SBA) respectfully requests $5.812 million in FY 2015 for the National Spina Bifida Program housed at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) and other related Spina Bifida initiatives. SBA is a national patient advocacy organization, working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. SBA stands 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 (NTD), occurs when the spinal cord fails to close properly within the first few weeks of 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 NTD 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, which helps 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 are due to breakthroughs in research, combined with improvements in health care and treatment. However, with this extended life expectancy, people with Spina Bifida now face new challenges, such as finding adult health care providers, education, job training, independent living, health care for secondary conditions, and aging concerns, among others. Fortunately, with the creation of the National Spina Bifida Program in 2003, individuals and families affected by Spina Bifida now have a program at the CDC that relates to their needs.

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. The CDC calculates that there are approximately 3,000 NTD births each year, of which an estimated 1,500 are Spina Bifida, 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. 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 will likely have a normal or near normal life expectancy. The CDC's National Spina Bifida Program works to improve quality-of-life for those living with Spina Bifida.

The National Spina Bifida Program helps provide 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 and executive function skills such as math. These problems can be treated or prevented, but only if those affected by Spina Bifida – and their caregivers – are properly educated to provide the skills leading to 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 estimated 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 Patient Registry, now in its third year. A total of 17 sites throughout the nation have collated over 3000 patient records from which lifesaving data about treatment and care can be extracted.

SBA understands that the Congress and the nation face unprecedented budgetary challenges. However, the progress being made by the National Spina Bifida Program must be sustained 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 $5.812 million (level funding) in FY 2015 to the program, so it can continue its current its current scope of work, increase its folic acid awareness/Spina Bifida prevention efforts, further develop the National Spina Bifida Patient Registry, and ensure that patients and their clinicians receive the most up-to-date information – all efforts that help improve quality of life and fulfill unmet needs for an estimated 166,000 Americans currently living 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 2015. 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.

Conclusion

Please know that SBA stands 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 2015 funding for programs that will improve the quality-of-life for the estimated 166,000 Americans and their families living with all forms of Spina Bifida.

The National AHEC Organization supports and advances the AHEC Network to improve health by leading the nation in the recruitment, training and retention of a diverse health workforce for underserved communities.

STATEMENT OF ROB TRACHTENBERG
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REGARDING FISCAL YEAR 2015 APPROPRIATIONS
FOR THE HEALTH RESOURCES AND SERVICES ADMINISTRATION'S TITLE VII
AREA HEALTH EDUCATION CENTER PROGRAM

SUBMITTED FOR THE RECORD TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE
ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES
MARCH 14, 2013

The members of the National AHEC Organization (NAO) are pleased to submit this statement for the record recommending **$75 million in FY 2015 for the Area Health Education Center (AHEC) program authorized under Titles VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA).** The NAO is the professional organization representing AHECs. The AHEC Program is an established and effective national primary care training network built on committed partnerships of 53 medical schools and academic centers. Additionally, 253 AHEC centers within 48 states and tens of thousands of community practitioners are affiliated with the AHEC's national clinical training network.

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, over 379,000 students have been introduced to health career opportunities, and over 33,000 mostly minority and disadvantaged high school students received more than 20 hours each of health career exposure. Over 44,000 health professions students received training at 17,530 community-based sites, and furthermore; over 482,000 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.

The National AHEC Organization supports and advances the AHEC Network to improve health by leading the nation in the recruitment, training and retention of a diverse health workforce for underserved communities.

Justification for Recommendations

The AHEC network is an economic engine that fuels the recruitment, training, distribution, and retention of a national health workforce. AHEC stands for JOBS.

- AHECs are critical in the recruitment, training, and retention of the primary care workforce.
- Research has demonstrated that the community-training network is the most effective recruitment tool for the health professions and those who teach remain longer in underserved areas and communities.
- AHECs are in almost every county in the United States.
- With the aging and growing population, the demand for primary care workforce is far outpacing the supply.
- AHECs continue to educate and train current workforce, as well as recruiting and preparing future workforce
- In 2012, AHEC's trained 476,585 Health Professionals in 48 states in 13,842 Health Professions Shortage Areas (HPSAs) -- 26.4% of those trained were physicians (125,818).
- In 2012, the AHEC's introduced nearly 403,000 students to the health careers professions and workforce from grades K-College.
- The AHEC network's outcomes are the backbone of the nation's community-based health professions training, with a focus on training primary care workforce.
- Continued funding for the AHEC program is necessary as demonstrated by 1) a growing unmet need for primary care doctors in rural areas, and 2) the use of the national network of AHEC programs to carry out administrative priorities.

1. The National Health Service Corps (NHSC), has been mentioned as a program that addresses the priority of increasing diversity in the health professions workforce in underserved and rural areas and addresses the end of the pipeline. The AHEC program engages in pre-pipeline, pipeline, and post-pipeline activities that works to move individuals through a health careers pathway and beyond, with a special focus on primary care doctors.
2. The national network of the AHEC program has been tasked with:
    - Training 13,000+ providers nationwide in OIF/OEF/OND Veteran's behavioral and mental health, substance abuse, traumatic brain injury and post-traumatic stress, for those not utilizing the VA system
    - Working with the Food and Drug Administration to educate healthcare professionals nationwide on proper opioid prescribing habits to address the epidemic of prescription drug abuse
    - HRSA has encouraged functional linkage between Bureau of Primary Care and Bureau of Health Professions Programs. AHECs have partnerships with over 1,000 Community Health Centers nationally to recruit, train, and retain health professionals who have the cultural and linguistic skills to serve in HRSA designated underserved areas
    - Affordable Care Act activities such as increasing the enrollment of individuals and educating providers nationwide on health insurance exchanges

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SUBMITTED TO:
HOUSE LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS SUBCOMMITTEE

REGARDING FISCAL YEAR 2015 APPROPRIATIONS FOR:
NATIONAL INSTITUTES OF HEALTH—NATIONAL HEART, LUNG, AND BLOOD INSTITUTE, THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Chairman Kingston and distinguished members of the Subcommittee, as you begin to craft the Fiscal Year 2015 (FY15) Labor-HHS-Education appropriations bill, the Sleep Research Society (SRS) is pleased to submit this statement for the record asking you to provide $32 billion for NIH, including a proportional increase for the National Heart, Lung, and Blood Institute (NHLBI), $1 million in funding for sleep disorders awareness and surveillance at the Centers for Disease Control and Prevention (CDC), full support for the National Center on Sleep Disorders Research (NCSDR), and implementation of the 2011 *NIH Sleep Disorders Research Plan.* These actions will ensure increased awareness of the importance of sleep and circadian rhythms and further the advancements being made by sleep researchers to better understand the relationship between sleep and health.

SLEEP RESEARCH SOCIETY

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,100 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep and health outcomes. We promote training and education in sleep research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

According to an Institute of Medicine's report entitled, "Sleep Disorder and Sleep Deprivation: An Unmet Public Health Problem" (2006), chronic sleep and circadian disturbances and disorders are a very real and relevant issue in today's society as they affect 50-70 million Americans across all demographic groups. Sleep deprivation is a major safety issue, particular in reference to drowsy driving, where it is a factor in 20% of motor vehicle injuries. The widespread effect of sleep disorders on every age group poses a public health risk, extending from the ability to learn to maintain a healthy lifestyle. Furthermore, it is important to recognize that sleep disorders and circadian disturbances are often an indicator of, or a precursor to other

major diseases and disorders including; obesity, diabetes, hypertension, cardiovascular disease, stroke, depression, bipolar disorder, and substance abuse. Another increasingly detrimental condition affecting 15% of the population is sleep-disordered breathing, including obstructive sleep apnea. Sleep apnea results in excessive daytime somnolence, poor performance, increased frequency of road traffic accidents, and arterial hypertension. Studies show that 85% of 725 troops returning home from Afghanistan and Iraq had a sleep disorder and the most common was obstructive sleep apnea (51%). If left untreated, obstructive sleep apnea has significant negative impacts on health, including early mortality.

NATIONAL INSTITUTES OF HEALTH

Due to the fact that sleep is a multi-disciplinary issue, many institutes and centers at NIH, utilize a portion of their funding to support sleep and circadian research. The majority of sleep research is coordinated by NHLBI, particularly the National Center on Sleep Disorders Research. An appropriation of $32 billion for NIH, and $3 billion for NHLBI, is needed to facilitate the continued growth and advancement in the sleep and circadian research portfolio.

The reason NCSDR is housed at NHLBI is due to the important link between sleep disorders and cardiovascular health. NCSDR supports research, health education, and research training related to sleep-disordered breathing and the fundamental function of sleep and circadian rhythms. Furthermore, NCSDR coordinates sleep research across NIH and with other federal agencies and outside organizations.

NCSDR's coordinating role between institutes is made possible through adequate funding. These research activities also have far reaching effects, beginning with training grants targeted towards undergraduate students and career development opportunities attracting top talent in doctoral programs. Sequestration has the potential to disrupt the research training pipeline by reducing the amount of K, T, and F series awards for new investigators. It could also disrupt the career development pipeline designed to train future investigators who are pursuing research in sleep disorders and circadian rhythms. It is important to fund NIH at $32 billion and NHLBI at $3 billion in FY15 so that we can continue these advancements in sleep and circadian research.

DEPARTMENT OF VETERANS AFFAIRS

It is also important to recognize that by increasing the federal commitment to sleep and circadian research, we can improve the health of those brave Americans who have served in uniform and are suffering from sleep disorders. Both obstructive sleep apnea and insomnia have a high prevalence among active-duty U.S. Armed Forces and among Veterans. Post-traumatic stress disorder and/or depression are highly prevalent in returning Iraq and Afghanistan combat Veterans. Sleep disturbance is a prominent symptom in these disorders. Traumatic brain injury is increasingly common in modern combat, and sleep disruption in the aftermath of TBI may have negative effects on long-term recovery of normal brain function.

The Department of Veterans Affairs (VA) has shown a commitment to collaborating with NIH on sleep research related to Post-Traumatic Stress Disorder (PTSD), Traumatic Brain Injury (TBI), and Gulf War Illness (GWI). This is highlighted in the fiscal year 2014 (FY15)

president's budget request detailing research initiatives in PTSD and TBI. The "Longitudinal Health Study of Gulf War Era Veterans" is one of the largest scientific research studies on chronic diseases and multi-symptom illnesses, including Gulf War Illness. Researchers found that prazosin, an inexpensive drug already used by millions of Americans for hypertension and prostate problems, improves sleep and reduces nightmares for veterans with PTSD. They continue to pursue activities such as the difference between female and male veterans with PTSD and possible intervention strategies to help veterans with TBI return to daily activities. One study described in the Veteran's Health Administration report *State of VA Research 2012*, found that 96 percent of veterans with chronic multi-symptom illnesses experienced sleep disordered breathing. By using continuous positive airway pressure (CPAP) these veterans reported reductions in pain and fatigue and improvements in cognitive function.

Sleep disruption, especially insomnia, is a contributing risk factor to the onset and severity of major mental health problems such as depression, bipolar disorder, substance abuse, PTSD, TBI, and suicide among the veteran population. It is important to continue supporting the sleep research endeavors of the VA through robust funding for the Medical and Prosthetic Research Program at $589 million.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC gathers important data on sleep disorders through their surveillance efforts under the Chronic Disease Prevention and Health Promotion program. Most notably, CDC hosts a National Sleep Awareness Roundtable (NSART) by promoting the importance of sleep through the production of state fact sheets, updating the CDC website, and disseminating information on sleep related topics. CDC also promotes awareness of sleep disorders and the dangers associated with sleep deprivation for the benefit of millions of Americans. Currently population-based data on the prevalence of circadian disruption and its relationship to disease risk is relatively limited. Please fund CDC at $7.8 billion including an allocation of $1 million solely for sleep awareness and surveillance activities within the Chronic Disease Prevention and Health Promotion program and within NSART, so that progress can continue in the areas of sleep disorders and disturbances, sleep awareness, and education to the public community.

NIH SLEEP DISORDERS RESEARCH PLAN

NCSDR published the *NIH Sleep Disorders Research Plan* in November of 2011 highlighting the implementation of pertinent sleep research goals to enable further advancements in the realm of sleep and circadian rhythm disorders. A Joint Task Force between the two leading organizations representing the sleep medicine and research community, Sleep Research Society (SRS) and American Academy of Sleep Medicine (AASM), has identified research opportunities that will have the highest impact on health within the plan.

The Plan recommends implementation of the following sleep research goals which will help us understand the function of sleep and inform individuals on healthier lifestyle choices:

- Advance the understanding of sleep and circadian functions and of basic sleep and circadian mechanisms, in both the brain and the body, across the lifespan.

- Identify genetic, pathophysiological, environmental, cultural, lifestyle factors, and sex and gender differences contributing to the risk of sleep and circadian disorders and disturbances, and their role in the development and pathogenesis of co-morbid diseases and disability.

- Improve prevention, diagnosis, and treatment of sleep and circadian disorders, chronic sleep deficiency, and circadian disruption, and evaluate the resulting impact on human health.

- Enhance the translation and dissemination of sleep and circadian research findings and concepts to improve health care, inform public policy, and increase community awareness to enhance human health.

- Enable sleep and circadian research training to inform science in cross-cutting domains, accelerate the pace of discovery, and the translation of enhanced therapies from bench to bedside to community.

Research activities and stakeholders addressed by the plan benefit from the encompassing range of NIH research, training, and outreach programs. Over the past two years, steps have been taken to implement portions of this research plan, but additional work needs to be done. SRS encourages you to recommend that this research plan continue to be implemented during FY15.

Thank you for the opportunity to submit the views of the sleep research community. Please do not hesitate to contact us should you have any questions or require additional information.

Testimony of Nicole Lamoureux, Executive Director, National Association of Free and Charitable Clinics Concerning the Department of Health and Human Services Appropriations for Fiscal Year 2015

Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

March 28, 2014

On behalf of the National Association of Free and Charitable Clinics (NAFC), I am pleased to submit this testimony regarding the Free Clinic Medical Malpractice Program ($40,000 allocation) and the 340B Drug Pricing Program ($17 million allocation) as outlined in the Health Resources Services Administration (HRSA) budget proposal for fiscal year (FY) 2015, and to highlight some policy provisions that would lessen the administrative and bureaucratic burden that distracts the NAFC and our clinics from our important mission of providing patient care.

The NAFC is the only nonprofit 501c(3) organization whose mission is solely focused on the issues and needs of the more than 1,200 Free and Charitable Clinics and the people they serve in the United States. Our clinics receive little to no state or federal funding; they do not receive HRSA 330 funds and are not Federally Qualified Health Centers (FQHCs) or Rural Health Centers (RHCs). 80% of our patients are 18-65 years old, 58% are women, 51% are Caucasian and 83% come from a working household. It should also be noted that 44% of our clinics have an operating budget under $100,000.

One of the most common misconceptions about how the United States will look after the full implementation of the Affordable Care Act (ACA) is that there will no longer be a need for Free and Charitable Clinics to continue to provide charity care as a vital component of the health care safety net. In fact, many are surprised to hear that according to the Congressional Budget Office,

there may be as many as 29 million people left that without access to affordable health care even after the ACA and the promise of expanded access.

Given these realities, Free and Charitable Clinics will remain an important part of the national health care safety net. Accordingly, it remains critical that the NAFC and our clinics continue to provide care to those who need it most, partnering with community, government, and private partners, so that our clinics can continue to build a healthy America – one patient at a time. At this time, Free and Charitable Clinics receive no federal funding support, but there are a few modest, and very appropriate steps that could be taken to help these vital components of the safety net reach wider audiences.

Free Clinics Medical Malpractice - Federal Tort Claims Act

According to the Health and Human Resources Administration (HRSA), Free Clinics that utilize volunteers are granted medical malpractice coverage through the Federal Tort Claims Act (FTCA) within the Health Insurance Portability and Accountability Act (HIPAA). Under the ACA, this coverage was extended to Free Clinic board members, officers, employees, and individual contractors. Free Clinic volunteers, board members, employees, and/or contractors who meet all the requirements may be sponsored by the Free Clinic and "deemed" a federal employee by HRSA for the purpose of FTCA medical malpractice coverage. FTCA deemed status provides the covered individual with immunity from medical malpractice lawsuits resulting from his/her subsequent performance of clinical medical, dental, or related functions within the scope of his/her work at the Free Clinic.

The FTCA program provides Free Clinics with the ability to recruit volunteers, staff and board members while offering much needed protection from medical malpractice claims. However, the

program does not cover the Free Clinic entity. What this means is that the Free Clinic entity, employees, volunteers, and board members are not automatically covered under the FTCA and the clinic must reapply for coverage annually for both existing and new individuals that join the clinic team. This process becomes burdensome and unnecessarily time-consuming for a clinic that is trying to provide health care at the grassroots community level. Therefore, the NAFC strongly encourages Congress to expand the current FTCA program to deem eligible Free Clinic entities as protected under the FTCA program. This modification in the law will allow clinics the freedom to automatically have volunteers, staff, and their board along with the clinic covered under the FTCA program, reducing the administrative and bureaucratic burden that detracts from the central goal of providing much needed patient care.

In addition, the NAFC encourages Congress to remove the current restrictive language regarding receipt of government funds, fee-for-service governmental programs and billing on a sliding fee scale that at this time disqualifies some clinics from malpractice coverage. For example, clinics that are providing screenings and care under programs such as the Breast and Cervical Cancer Screening Program, Ryan White program, and Homeless programs are currently ineligible for FTCA coverage because they are considered fee-for-service government programs. Also, clinics that charge/bill on a sliding fee scale, but do not turn any patient away due to inability to pay, are also ineligible to receive coverage under the current FTCA program. By removing these restrictions, Congress will allow clinics to redirect their resources and time to caring for more patients in their communities.

In an effort to clarify those entities covered by the FTCA, we would like Congress to use the following definition of a Free & Charitable Clinic:

"Free and Charitable Clinics are safety net health care organizations that utilize a volunteer/staff model to provide a range of medical, dental, pharmacy, vision and/or behavioral health services to economically disadvantaged individuals. Such clinics are 501(c)(3) tax-exempt organizations, or operate as a program component or affiliate of a 501(c)(3) organization. Entities that otherwise meet the above definition, but charge a nominal/sliding fee to patients, may still be considered Free or Charitable Clinics provided essential services are delivered regardless of the patient's ability to pay. Free or Charitable Clinics restrict eligibility for their services to individuals who are uninsured, underinsured and/or have limited or no access to primary, specialty or prescription health care."

Using this new definition, along with the understanding that in the last 20 years there have been less than 5 claims to the Free Clinics Medical Malpractice program, there will be no significant expansion of the risk exposure to medical malpractice claims for the government. Expansion of HRSA's Free Clinic Medical Malpractice Program will allow Free and Charitable Clinics to redirect resources, currently allocated to malpractice insurance premiums and regulatory compliance, into expanded service for the nation's uninsured.

Expansion of the 340B Drug Pricing Program to Include Free and Charitable Clinics

The federal 340B Drug Pricing Program was created by Congress to provide substantial discounts on outpatient prescription drugs to entities serving the nation's most vulnerable patient populations. The program allows covered entities to receive anywhere from 25-50% discounts on medication and medical products for their patients. **"Eligible health care organizations/covered entities"** are defined in statute and include "HRSA-supported health centers and look-alikes, Ryan White clinics, State AIDS Drug Assistance programs, Medicare/Medicaid Disproportionate

Share Hospitals, children's hospitals, and ***other safety net providers***."

Currently, Free and Charitable Clinics are not deemed as within the ***other safety net providers*** category and are not eligible to participate in the existing 340B Drug Pricing Program. The 340B program is expressly designed to allow safety net entities to provide care for the country's most vulnerable patients, and the NAFC strongly encourages Congress to expand 340B program eligibility to include our Free and Charitable Clinics as entities that can participate in this much-needed relief, allowing NAFC Free and Charitable Clinics to serve on a level playing field with their peers who may already receive various kinds of federal funding.

Annually, Free & Charitable Clinics provide 5.5 million patient visits to the medically underserved by utilizing tens of thousands of volunteers, and we estimate that Free and Charitable Clinics spend $15 million annually on pharmaceutical and medical products for their patients.

Expanding the 340B Drug Pricing Program will allow Free & Charitable Clinics to provide services to their patients in the most cost-efficient and effective manner, and allow those savings to be put back into providing care for even more of the underserved.

Free and Charitable Clinics are a crucial part of America's healthcare safety net and organize on a grassroots community level; they are providing healthcare daily to many deserving and hardworking individuals who fall through the cracks of our healthcare system. The NAFC and our members are grateful for the opportunity to share our thoughts with the committee on the FY 2015 appropriations legislation, and look forward to partnering to provide access to high quality healthcare to those who need it most.

HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

TESTIMONY BY
THE HUMANE SOCIETY OF THE UNITED STATES
ON THE FY 2015 BUDGET – NATIONAL INSTITUTES OF HEALTH
March 28, 2014

Contact: Kate Wall, The Humane Society of the United States, Federal Affairs
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On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), we appreciate the opportunity to provide testimony on our top NIH funding priorities for the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in Fiscal Year 2015.

CAPACITY AT THE NATIONAL CHIMPANZEE SANCTUARY FOR FEDERALLY-OWNED CHIMPANZEES RETIRED BY THE NATIONAL INSTITUTES OF HEALTH

The HSUS and HSLF request NIH be given authority to use funds appropriated in this and subsequent appropriations bills for extramural construction and renovation within the National Chimpanzee Sanctuary System. In 2013, NIH announced their plan to retire hundreds of government owned chimpanzees to sanctuary. This decision followed years of scientific review which determined chimpanzees are not necessary for research. Additional sanctuary construction is needed to enable NIH to move forward with their plan to retire the vast majority of government owned chimpanzees. Even with upfront construction expenditures, transferring government owned chimpanzees from laboratories to sanctuaries will save significant taxpayer funds over the lifetimes of the chimpanzees.

Further basis of our request can be found below.

Background information

In June of 2013, the National Institutes of Health announced their plan to retire all but 50 government-owned chimpanzees to sanctuary, significantly curtail the use of chimpanzees in NIH funded studies and not to revitalize breeding of chimpanzees for research. These decisions resulted from an Institute of Medicine study in 2011 which found that chimpanzees are not necessary for the vast majority of research. Immediately following the announcement of the IOM study results, NIH accepted the findings and assembled a panel of experts to advise them on the best way to implement the IOM findings. NIH ultimately accepted nearly all of the expert panel's recommendations in their final decision.

Prior to announcing their plan, NIH had already begun the transfer of the 110 government owned chimpanzees at the New Iberia Research Center in Louisiana to Chimp Haven (the National Chimpanzee Sanctuary), also located in Louisiana. The transfer is expected to be completed by the end of fiscal year 2014. At that point, approximately 350 government-owned chimpanzees will remain in laboratories—300 of whom will be slated for retirement to sanctuary per NIH's plan.

In late November of 2013, the President signed into law amendments to the Chimpanzee Health Improvement Maintenance and Protection (CHIMP Act) which provided continued funding for the care, maintenance and transportation of federally owned chimpanzees over the next five years. These amendments have enabled NIH to use their funding judiciously by continuing to support chimpanzees in sanctuary and also set the stage for NIH to move forward with their plan to retire hundreds more chimpanzees.

Costs in laboratories vs. sanctuary

Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in barren labs (see chart below). It is estimated that

transferring the 300 government-owned chimpanzees who are slated for retirement from the laboratories where they are currently housed to the national sanctuary would save taxpayers anywhere from $1.7 million to $2.7 million per year in care and maintenance costs.

Construction to house more chimpanzees in sanctuary will require an upfront expenditure. However, due to the lower per diem cost in sanctuary, retiring chimpanzees to sanctuary will still yield a significant savings to taxpayers over the long term. The sooner the construction is completed and the chimpanzees are moved to sanctuary, the more the government will save over the lifetimes of the chimpanzees—which can be up to 60 years.

Estimated Costs Related to Care and Maintenance of Government Owned Chimpanzees:

Government Owned Chimpanzees in Research Facilities and Research Reserve Facilities			
Facility	**# of chimpanzees**	**NIH cost, $M/year**	**NIH cost, $/chimpanzee/day**
New Iberia Research Center	59[1,2]	1.01[3]	46.7[4]
Keeling Center for Comparative Medicine and Research	147[2]	2.44[3]	45.4
Keeling Center for Comparative Medicine and Research, DVR grant	16[2]	0.4[2]	68.8
Southwest National Primate Research Center, U42 grant[5]	22[2]	0.65[3]	80.9
Alamogordo Primate Facility	162[2]	3.60[2]	61.3
Totals	**406**	**8.10**	**Average: 54.7**

Government Owned Chimpanzees in Sanctuary			
Facility	**# of chimpanzees**	**NIH cost, $M/year**	**NIH cost, $/animal/day,**
Chimp Haven	**118-153[6]**	**1.7[7]**	**30-39**

[1] The remaining 59 chimpanzees at New Iberia Research Center are scheduled to be moved to Chimp Haven by the end of FY 2014
[2] Based on information available on NIH website regarding chimpanzee maintenance costs for FY 2014
[3] Based on data available in NIH Research Portfolio Online Reporting Tools (RePORT) for FY 2014
[4] Figure expected to increase significantly as chimpanzees move to Chimp Haven and funds are spread over fewer chimpanzees
[5] In addition to this grant, NIH also supports an additional 91 chimpanzees at the facility. These chimpanzees are owned by the laboratory and are not under the control of NIH.
[6] Fifty chimpanzees from New Iberia Research Center were transferred to Chimp Haven during this contract year.
[7] Unlike the other facilities, Chimp Haven has a cost reimbursement contract in which they are reimbursed for costs incurred. This number represents actual costs billed to NIH over the most recently completed contract year (06/30/2012 - 06/29/2013)

We are currently working with interested stakeholders to draft language that addresses the issue of allowing chimpanzees to retire into the sanctuary system. In the interim, we respectfully request the subcommittee to consider the following placeholder language:

Funds provided to the National Institutes of Health in this and subsequent Acts may be used to support the sanctuary system established by Section 404K of the Public Health Service Act, including for care, maintenance, and transportation (as authorized in Public Law 113-55), and for the construction and renovation of the sanctuary system.

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2015. We hope the Committee will be able to accommodate this request. Thank you for your consideration.

HIGH THROUGHPUT SCREENING, TOXICITY PATHWAY PROFILING, AND BIOLOGICAL INTERPRETATION OF FINDINGS
NATIONAL INSTITUTES OF HEALTH – OFFICE OF THE DIRECTOR

In 2008, NIH, NIEHS and EPA signed a memorandum of understanding 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, including FDA joining the MOU, 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, which is supported by The HSUS, HSLF, and the American Chemistry Council.

NIH Director

The Committee supports NIH's leadership role in modernizing the approach for evaluating the safety of pharmaceuticals and chemicals based on the incorporation of advanced molecular biological and computational methods that envisions a move away from animal tests. NIH has indicated that development of this science is critical to several of its priorities, from personalized medicine to tackling specific diseases such as cancer and diabetes and including critical initiatives such as BRAIN and the National Center for Advancing Translational Sciences. The Committee encourages NIH to continue to expand both its intramural and extramural support for the use of human biology-based experimental and computational approaches in health research to further define human biology, disease pathways, and toxicity and to develop tools for their integration into clinical strategies and safety determination paradigms. Extramural and intramural funding should be made available for the development and evaluation of the relevance and reliability of human biology-based and pathway approaches and prediction tools to assure readiness and utility for regulatory and clinical applications, including pilot studies of pathway-based risk assessments. The Committee requests an update on current activities, a plan for future activities, and the fiscal year 2015 funding level for this area of research in the fiscal year 2016 congressional budget justification.

CONEG
COALITION OF NORTHEASTERN GOVERNORS

Statement of the Coalition of Northeastern Governors
to the
Subcommittee on Labor, Health and Human Services, Education,
and Related Agencies
Committee on Appropriations
United States House of Representatives
Regarding FY2015 Appropriations for the
Low Income Home Energy Assistance Program (LIHEAP)
March 28, 2014

The Coalition of Northeastern Governors (CONEG) is pleased to share with the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies its views regarding the FY2015 appropriations for the Low-Income Home Energy Assistance Program (LIHEAP).

The CONEG Governors appreciate the Subcommittee's long-standing support for this vital program, and recognize the difficult fiscal decisions that face the Subcommittee. In recognition of the on-going challenges that the most vulnerable low-income households in our region face in heating their homes, the Governors urge the Subcommittee to fund the LIHEAP core block program in FY2015 at the authorized level of $5.1 billion but not less than $4.7 billion. In addition, the Governors request sufficient contingency funds to address unforeseen energy emergencies such as prolonged severe weather or price spikes in home heating fuels. Adequate, predictable and timely federal funding is essential for LIHEAP to provide a vital lifeline to those households struggling to afford the basic necessity of home energy. The Governors urge the Subcommittee to provide these funds in a manner consistent with the LIHEAP statutory objective: "to assist low-income households, particularly those with the lowest incomes that pay

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a high proportion of household income for home energy, primarily in meeting their immediate home energy needs."

LIHEAP funds are targeted to those households with the greatest energy burden. Most LIHEAP assistance is targeted to households whose income is less than 150 percent of the federal poverty level, which for a two-person household is $23,595 in 2014. However the majority of LIHEAP recipients have incomes far below that level. Many of these households live on fixed incomes and are not likely to benefit from improvements in the job market and the national economy. More than ninety percent of LIHEAP households have at least one vulnerable member – the elderly or disabled and young children – for whom temperature extremes could have serious health and safety consequences. Approximately 20 percent of LIHEAP households contain at least one member who is a military veteran.

Low-income households across the nation spend a disproportionate amount of their income on home energy, often over three times more than non-low-income households. The AARP estimates low-income senior households (age 65 and older) heating with fuel oil will spend almost 20 percent of household income on heating costs, while all other households heating with fuel oil will spend roughly 5 percent of their income to heat their homes. In the colder climates of the Northeast, the average household typically uses 800 gallons of heating oil per winter. At EIA's projected average cost of $3.83 per gallon, an elderly LIHEAP recipient whose primary income is a Social Security check would need to spend almost three months of income to heat her home this winter. Many seniors will spend more than one-third of their monthly income just to get the minimum 100-gallon delivery of heating oil.

The energy burden faced by low-income households is particularly acute in the Northeast. This region experiences some of the nation's highest home heating bills due to a combination of the extended winter heating season and heating fuel expenditures that typically exceed national averages. According to the Energy Information Administration (EIA), the average consumer expenditures for heating fuels in the Northeast have consistently and significantly exceeded similar expenditures in all other regions regardless of the type of fuel used – natural gas, heating oil, propane, or electricity.

Low-income households in the Northeast experience another aspect of "energy burden". More than any other region of the country, Northeast households are dependent upon delivered fuels – heating oil, propane and kerosene. The 30 percent of Northeast households that rely upon delivered fuels account for approximately 80 percent of the homes nationwide that use home heating oil. These heating fuels are also the most expensive and volatile in price. The EIA estimates that households using heating oil can expect to pay $2,243 to keep warm this winter. The EIA also finds that households using delivered fuels see any change in wholesale prices reflected in their energy bills almost immediately, unlike natural gas and electricity retail customers. These "delivered fuel" households experience another vulnerability compared to natural gas and electricity customers. Low-income households that use delivered fuels are less likely to have the option of payment plans, access to utility assistance programs, and the protection of utility service shut-off moratoria during the heating season. If LIHEAP funds are not available to these households, the fuel delivery truck simply does not come.

The Northeast has some of the country's oldest homes and coldest climates. Reducing home energy costs presents unique challenges to northeast states. State LIHEAP programs, often working with their Weatherization Assistance Programs, help low-income households take steps to reduce their energy use and lower their energy bills. Unlike the federal weatherization program, LIHEAP funds can be used to provide repair or replace inefficient, unsafe and non-working home heating systems – improvements that enhance the safety and reduce the energy use of low-income households.

Even with these programs to reduce energy use, many of the lowest income families that benefit from LIHEAP have limited options to reduce their energy bills. Some older homes, especially older manufactured homes, have structural issues that make them ineligible for weatherization assistance. Throughout the region, many LIHEAP households have limited ability to switch to more energy efficient heating systems due to the lack of adequate resources for the upfront costs and the lack of access to less expensive heating fuels. For example, natural gas may provide a less expensive energy source to heat homes, but conversion is neither simple nor affordable for low-income households. The New England Fuel Institute estimates that converting a complete home heating system from oil to natural gas can cost as much as $10,000. In addition, homes in rural and metropolitan areas throughout the Northeast are not served by natural gas infrastructure.

State LIHEAP programs continue to seek innovative and efficient ways to "do more with less" and stretch scarce LIHEAP dollars to ensure that meaningful assistance can be provided to those households with the greatest needs. For example, LIHEAP funds are frequently leveraged by

utility assistance programs for low-income households. States in the Northeast have worked with utilities to develop payment plans to reduce arrearages and lessen the prospect of utility shut-offs after the heating season ends. They have negotiated with fuel dealers to receive discounts on deliverable fuels, and have entered into agreements to purchase fuel in the summer when prices are lowest. LIHEAP is one of the most efficiently run programs with low overhead costs. Even after taking significant cost-cutting steps, states have had to take actions such as tightening program eligibility, closing the program early, and reducing benefit levels.

In summary, the CONEG Governors appreciate the Subcommittee's continued support for LIHEAP, and urge you to fund the core block grant at the authorized level of $5.1 billion, but not less than $4.7 billion, and sufficient contingency funds to address unforeseen energy emergencies.

Written Testimony of the Coalition of Nutrition Services Agencies (CNSA) for the Subcommittee on Labor, Health and Human Services, Education, and Related Agencies of the Committee on Appropriations for FY 2015

U.S. Senate – Department of Health and Human Services

On behalf of the Coalition of Nutrition Services Agencies (CNSA), I am pleased to submit this testimony to the Members of this Subcommittee on the urgency of increased funding for the domestic HIV/AIDS portfolio in Fiscal Year 2015 (FY15). This funding will be critical to achieving the goals of the National HIV/AIDS Strategy (NHAS). Moreover, increased funding will ensure that the NHAS' vision of the United States in the future as "a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life extending care, free from stigma and discrimination" can become reality.

CNSA supports the domestic HIV/AIDS portfolio funding levels specified in testimonies submitted by the AIDS Budget and Appropriations Coalition and AIDS United.

The Coalition of Nutrition Services Agencies (CNSA) is a national association of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. Collectively, we deliver approximately 10 million meals to PLWHA across the country each year. CNSA is committed to increasing awareness of the essential roles that both food and nutrition services (FNS) and Medical Nutrition Therapy (MNT) play in successfully treating HIV/AIDS, and to expanding access to these critical interventions.

As implementation of the Affordable Care Act (ACA) continues at the federal and state levels, and as challenges to and changes in access to medical care and care completion services for PLWHA multiply, ongoing investment in the Ryan White Program will be essential to ensure that the U.S. can continue to address the disparities that exist at each level of the HIV/AIDS Treatment Cascade. Ongoing investments in the Ryan White Program will also ensure that the successful care delivery infrastructure that has developed through the learned experience and expertise of Ryan White Program providers in finding people living with HIV, linking them to care and ensuring effective treatment will continue to save lives and eventually end the HIV/AIDS epidemic.

Food and nutrition services and medical nutrition therapy provided through the Ryan White Program are crucial to the achievement of an AIDS-Free Generation.

In addition to providing direct medical care, the Ryan White Program also provides important funding for food and nutrition services as part of the holistic model of care that has been the hallmark of the nation's response to HIV/AIDS. The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-

depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian (RD) outside of a primary care visit. FNS encompass home-delivered meals, congregate meals, grocery bags, food pantries and vouchers that complement and are necessary to the fulfillment of MNT.

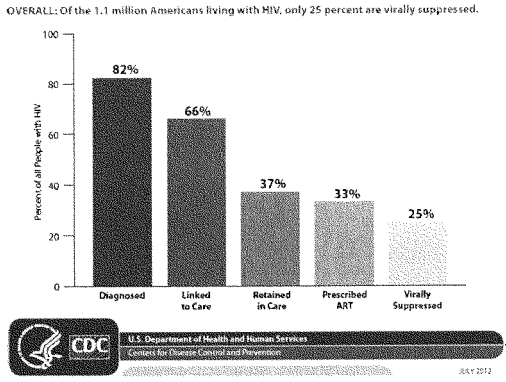
Since 2006, MNT and FNS, provided under the guidance of RDs, have been included as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression. These interventions are also critical to allowing PLWHA to remain in their communities and out of more expensive inpatient medical institutions such as hospitals and nursing homes. Available hospital cost data indicates that the provision of FNS would result in potential savings in the magnitude of billions of dollars for HIV/AIDS alone. They also find that the relatively low cost of FNS programs makes a strong argument for maximal implementation and utilization[i]. In particular:

Access to FNS and MNT for PLWHA is critical to fulfilling the goals of the NHAS

1. **NHAS Goal: Reducing new HIV infections:** PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96% of the time[ii], thus, FNS is key to prevention[iii].
2. **NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV:** PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[iv].
3. **NHAS Goal: Reducing HIV-related disparities and health inequities:** By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities[v].

FNS and MNT are essential to addressing each step of the HIV/AIDS Treatment Cascade

The HIV Treatment Cascade is a way to show, in visual form, the proportion of individuals living with HIV/AIDS who are engaged at each stage of HIV care, and to identify issues and opportunities related to improving the delivery of services to PLWHA across the entire continuum of care. FNS adequately addresses medical issues at each of the five stages:



1. **Stage one - only 82% of PLWHA are diagnosed:** FNS is often the gateway to care. People who have access to food are more likely to be in care and thus diagnosed. Preliminary data also appears to show a higher incidence of infection among the food insecure[vi].
2. **State two - only 66% are linked to care**: Access to FNS is often the reason that PLWHA get connected to care, because being active in care is a requirement of receipt of FNS through Ryan White.
3. **Stage three - only 37% are retained in care**: The research above demonstrates that food secure PLWHA are more likely to maintain their care (causation, not correlation).
4. **Stage four - only 33% are prescribed ART:** Food insecurity in PLWHA is independently linked to non-adherence.
5. **Stage five - only 25% are virally suppressed:** Food insecure PLWHA are less likely than food secure PLWHA to have undetectable viral loads (controlled).

The cited research below further demonstrates that access to FNS for PLWHA is good policy along the continuum of care from prevention to treatment, even in environments where people have better access to medical care.

For PLWHA, food insecurity (defined as a PLWHA not having enough money for food that they or their family need; or as sometimes or more often not having enough to eat, or having gone a whole day without anything at all to eat in the past 30 days, or reporting a continuing need for assistance regarding food, groceries or meals) leads to:

- Lower CD4 counts & lower likelihood of having undetectable viral loads[vii]
- More ER visits[viii] & increased morbidity and mortality[ix]
- More missed primary care appointments & reduced use of antiretroviral therapy[x]

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines[xi].

FNS and MNT are critical interventions that reduce healthcare costs and lead to healthcare savings.

Millions of dollars in healthcare expenditures are saved through the provision of medically tailored meals: One study demonstrated that the six months after initiation of FNS, average monthly health care costs for PLWHA fell from $50,000/month to approximately $17,000/month[xii]. Additionally:

- Access to FNS decreased all clients' (including PLWHA and individuals with other critical and chronic illnesses such as cancer) average monthly healthcare costs, which fell an average of 62% during clients' first three months on the program.
- If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37% and they were 20% more likely to be able to be discharged to their homes rather than a more expensive institution.

Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[xiii] and the resulting decreases in their healthcare costs. For example, four studies regarding MNT have demonstrated improved outcomes related to energy intake and/or decreased symptoms (with or without oral nutritional supplementation) and cardiovascular risk indices, especially with increased frequency of MNT visits[xiv]. In addition, two studies regarding nutritional counseling (non-MNT) also reported improved outcomes related to weight gain, CD4 count, and quality of life[xv].

The bottom line, MNT and FNS improve health and save healthcare dollars:

- by mitigating the need for expensive home care for individuals whose only need is nutrition, and by complementing and, therefore, reducing home care needs in other situations;
- by decreasing clients' use of emergency room, hospital and nursing home care; and
- through reductions in preventable hospital admissions and readmissions of individuals.

FNS is also a low cost intervention:

- FNS = $20/day vs. hospital stay at $4,000/day
- FNS = $20/day vs. cost of a home health aide at $18/hour
- By preventing one day of hospitalization, you can feed an individual a diet medically-tailored for their unique needs for more than half the year.

In addition, malnutrition is a leading cause of hospitalization in the US for all individuals, with 1 in 3 people in the US admitted to the hospital malnourished[xvi]. Death rates are higher among HIV-infected clients with malnutrition, including those receiving antiretroviral therapies (ARTs)[xvii]. A well-nourished person with HIV who has a controlled viral load is more likely to be able to withstand the effects of HIV infection, supporting immune status and possibly delaying the progression of HIV disease[xviii]. The negative effects of malnutrition are often preventable and are usually not easily reversed. Nutrition-related alterations can occur early in HIV infection; thus, nutrition intervention should begin soon after diagnosis.

Ongoing support and investment in the Ryan White Program is particularly important because FNS, MNT and other crucial care-completion services that depend on this funding

are not included as covered services in the majority of the benefit packages provided by Medicaid and other public insurance initiatives that will be expanded by the ACA.

Without the Ryan White Program and its financial support of care completion services, the achievements we have made in addressing the Treatment Cascade will be lost. FNS and other care completion services are essential throughout the life of a client to ensure that medical care and treatment will be successful. It is critical to both individual client and public health that we keep the Ryan White FNS Program strong. Without the Ryan White Program, these and many other vital services will no longer be available to the millions of PLWHA who desperately depend on them to stay alive. Losing these services will result in the deterioration of individual and public health and ultimately roll back the tide on the critical advances this nation has made in transforming HIV/AIDS from a death sentence to a chronic illness, taking us even further away from the goal of an AIDS Free Generation.

CNSA is deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS and MNT, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate MNT and FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces health care costs.

CNSA appreciates the opportunity to offer testimony regarding the FY 2015 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library. **On behalf of our members and partners, I urge the Subcommittee to consider and support the FY2015 funding levels that have been outlined by the AIDS Budget and Appropriations Coalition and AIDS United.**

Thank you.

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[iv] New data (2013) from The Community Health Advisory & Information Network, which is an ongoing prospective study of representative samples of persons living with HIV/AIDS in New York City and the Tri-County region of Westchester, Rockland and Putnam Counties. CHAIN is conducted by researchers from Mailman School of Public Health at Columbia University in collaboration with the New York City Department of Health and Mental Hygiene,

Public Health Solutions, Inc. and the Westchester County Department of Health as part of evaluation activities of the New York Health and Human Services Planning Council.

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Testimony of the Puyallup Tribe of Indians
Tribal Chairman Herman Dillon, Sr.
House Committee on Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies
Fiscal Year 2015
March 25, 2014

The Puyallup Tribe of Indians, a federally recognized Indian tribe with a reservation in Tacoma, Washington, appreciates the opportunity to provide testimony in support of the reauthorization of the Teaching Health Center Graduate Medical Education program (THC GME). This program was authorized by section 340H of the Public Health Service Act, and is administered by the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services. The purpose of this program is to increase the number of primary care providers trained in under-served, community-based ambulatory health care centers. The five-year program was initially funded at $230 million, and is set to sunset on September 30, 2015. The Puyallup Tribe fully supports a five-year or permanent reauthorization of the THC GME program funded at an amount of up to $800 million per fiscal year

As noted in a recent HRSA publication:

The current supply of the primary care workforce is insufficient to meet the health needs of the United States population, especially among those who seek care in community settings. In its June 2010 Report to Congress, the Medicare Payment Advisory Commission (MedPAC) called for increasing the amount of graduate medical education (GME) time spent in non-hospital settings, along with changes to GME funding, to meet community-based care goals and increase the diversity of the pipeline of health professionals (MedPAC, 2010).

In its short existence, the THC GME program is proving to be a valuable federal program to address the shortage of primary care providers across the nation. There are currently more than 30

THC GME programs being operated in more than 20 states, including Alabama, Arkansas, Connecticut, California, and Washington, to name a few.

In addition, the program is proving to be a valuable avenue by which to address the chronic, historic shortage of primary care providers in the Indian health system, and across Indian Country generally. The shortage of primary care providers in Indian Country has been well documented, and remains a constant issue as demonstrated by a recent August 2013 address by the Director of the Indian Health Service. (See http://www.ihs.gov/newsroom/includes/themes/newihstheme/display_objects/documents/2013_Speeches/IndianHealthPartnershipsAugust32013.pdf).

The Puyallup Tribe oversees a full-service, nationally-accredited ambulatory health care center located in Tacoma, Washington, managed by the Puyallup Tribal Health Authority (PTHA), a non-profit entity of the Tribe. PTHA provides medical, dental, pharmacy, laboratory, X-ray, counseling, and addiction treatment services to more than 20,000 Native Americans in and around Tacoma. In its decades of operation, PTHA has developed into an outstanding full-service health center for the neediest of patients having the greatest health disparities.

In 2011, PTHA, with the support of the Puyallup Tribal Council, eagerly applied for and was granted an HRSA THC GME grant to establish a THC GME program at our Tribal clinic. The program was the first-of-its-kind housed at a Native community care clinic. The purpose of the Puyallup Tribal Family Medicine Residency Program is (1) to train family practice physicians who are culturally sensitive and comfortable practicing in Native communities, and (2) to expand medical services and access to quality health care in our community. This was not only to train our own physicians as part of the PTHA's succession planning, but also to help address the primary care physician shortage in Native communities across the country. By exposing these residents to Native communities early in their careers, we believe they will be instilled with a passion to serve these communities throughout their careers.

Within the first few months of establishing the program, it proved so successful within our community that the Tribal Council approved doubling the program's size from two residents per academic year to four. The Tribe's program currently has six residents, and at full capacity will have twelve residents.

Again, the Puyallup Tribe strongly supports the reauthorization of the THC GME program on a five-year or permanent basis, and funding for each fiscal year at an amount of up to $800 million. By allowing the THC GME program to sunset on September 30, 2015, one of the few avenues currently available to address the shortage of primary care providers in Indian Country and across the nation generally will end, while the need to address the current, insufficient supply of primary care providers will remain.

HOUSE COMMITTEE ON APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

WRITTEN TESTIMONY FOR THE RECORD
ANIMAL PROTECTION OF NEW MEXICO
ON THE FY 2015 BUDGET – NATIONAL INSTITUTES OF HEALTH
March 28, 2014

Laura Bonar, Animal Protection of New Mexico & Animal Protection Voters, Program Director
PO Box 11395, Albuquerque, NM 87192 *505-401-8936 / laura@apnm.org*

On behalf of the board, staff, members and supporters of Animal Protection of New Mexico (APNM) and Animal Protection Voters (APV), we sincerely appreciate the opportunity to provide testimony on our top NIH funding priority for the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in Fiscal Year 2015.

CAPACITY FOR FEDERALLY-OWNED CHIMPANZEES RETIRED BY THE NATIONAL INSTITUTES OF HEALTH

APNM and APV request NIH be given authority to use funds appropriated in this and subsequent appropriations bills for construction and renovation within the National Chimpanzee Sanctuary System.

In 2013, NIH announced their plan to retire hundreds of government owned chimpanzees to sanctuary. This decision followed years of scientific review that determined chimpanzees are not necessary for research to advance human health along with broad public outcry over the ethics of holding chimpanzees in labs. Additional sanctuary construction is needed to enable NIH to move forward with their plan to retire the vast majority of government owned chimpanzees. Even taking into account upfront construction expenditures, the sooner the construction is completed and the chimpanzees are moved to sanctuary, the more the government will save over the lifetimes of the chimpanzees—which can be 60 years or more.

Background information

In June of 2010, the National Institutes of Health proposed a plan to move 202 aging, sick chimpanzees from a facility New Mexico where they had not been used for invasive research for years to a laboratory in Texas for further research. Intense public scrutiny over the animal cruelty issues and taxpayer waste of this plan was bolstered by involvement from New Mexico Governor Bill Richardson, Dr. Jane Goodall, and many more. In December 2010 U.S. Senators Tom Udall, Tom Harkin, and Jeff Bingaman requested an independent study from the National Academy of Sciences on whether chimpanzees are necessary as invasive research subjects.

The December 2011 Institute of Medicine study found that chimpanzees are not necessary for the vast majority of research and noted the intense ethical objections raised by keeping chimps in research labs. Immediately following the announcement of the IOM study results, NIH accepted the findings and assembled a panel of experts to advise them on the best way to implement the IOM findings. NIH accepted nearly all of the expert panel's recommendations in their final decision. In June of 2013, the National Institutes of Health announced their plan to retire all but 50 government-owned chimpanzees to sanctuary, significantly curtail the use of chimps in NIH funded studies and not to revitalize breeding of chimpanzees for research.

NIH had already begun the transfer of the 110 government owned chimpanzees at the New Iberia Research Center in Louisiana to Chimp Haven (the National Chimpanzee Sanctuary), also located in Louisiana. This transfer is scheduled to be completed by the end of fiscal year 2014.

At that point, approximately 350 government-owned chimpanzees will remain in laboratories—300 of whom are slated for retirement to sanctuary per NIH's plan.

In late November of 2013, the President signed into law amendments to the Chimpanzee Health Improvement Maintenance and Protection (CHIMP Act) which continued funding for the care, maintenance and transportation of federally owned chimpanzees over the next five years. These amendments have enabled NIH to provide funds for basic care for chimpanzees the agency already approved into sanctuary and also set the stage for NIH to move forward with their plan to retire hundreds more chimpanzees.

Costs in laboratories vs. sanctuary

Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in research laboratories (see chart below). It is estimated that transferring the 300 government-owned chimpanzees who are slated for retirement from the laboratories where they are currently housed to the national sanctuary will save taxpayers $1.7 million to $2.7 million per year in care and maintenance costs.

Construction to house more chimpanzees in sanctuary will require an upfront expenditure. However, due to the lower per diem cost in sanctuary, retiring chimpanzees to sanctuary will still yield a significant savings to taxpayers. The sooner construction is completed and the chimpanzees are moved to sanctuary, the more the taxpayers will save.

Estimated Costs Related to Care and Maintenance of Government Owned Chimpanzees:

Government Owned Chimpanzees in Research Facilities and Research Reserve Facilities			
Facility	**# of chimpanzees**	**NIH cost, $M/year**	**NIH cost, $/chimpanzee/day**
New Iberia Research Center	59[1,2]	1.01[3]	46.7[4]
Keeling Center for Comparative Medicine and Research	147[2]	2.44[3]	45.4
Keeling Center for Comparative Medicine and Research, DVR grant	16[2]	0.4[2]	68.8
Southwest National Primate Research Center, U42 grant[5]	22[2]	0.65[3]	80.9
Alamogordo Primate Facility	162[2]	3.60[2]	61.3
Totals	**406**	**8.10**	**54.7 (average)**

Government Owned Chimpanzees in Sanctuary			
Facility	**# of chimpanzees**	**NIH cost, $M/year**	**NIH cost, $/animal/day,**
Chimp Haven	**118-153[6]**	**1.7[7]**	**30-39**

We are currently working with interested stakeholders to draft language that addresses the issue of allowing chimpanzees to retire into the sanctuary system. In the interim, we respectfully request the subcommittee to consider the following placeholder language:

Funds provided to the National Institutes of Health in this and subsequent Acts may be used to support the sanctuary system established by Section 404K of the Public Health Service Act, including for care, maintenance, and transportation (as authorized in Public Law 113-55), and for the construction and renovation of the sanctuary system.

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[1] The remaining 59 chimpanzees at New Iberia Research Center are scheduled to be moved to Chimp Haven within the next year
[2] Based on information available on NIH website regarding chimpanzee maintenance costs for FY 2014
[3] Based on data available in NIH Research Portfolio Online Reporting Tools (RePORT) for FY 2014
[4] Figure expected to increase significantly as chimpanzees move to Chimp Haven and funds are spread over fewer chimpanzees
[5] In addition to this grant, NIH also supports an additional 91 chimpanzees at the facility. These chimpanzees are owned by the laboratory and are not under the control of NIH.
[6] Fifty chimpanzees from New Iberia Research Center were transferred to Chimp Haven during this contract year.
[7] Unlike the other facilities, Chimp Haven has a cost reimbursement contract in which they are reimbursed for costs incurred. This number represents actual costs billed to NIH over the most recently completed contract year (06/30/2012 - 06/29/2013)

We appreciate the opportunity to share testimony with the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2015. We hope the Committee will accommodate this request to benefit chimpanzees and American taxpayers. Thank you for your service and your kind consideration.

House Committee on Appropriations Subcommittee on
Labor, Health and Human Services,
Education and Related Agencies
"2015 Appropriations Testimony"
Friday, March 28, 2014
Written Testimony of
THE HONORABLE W. RON ALLEN, TRIBAL CHAIRMAN/CEO
JAMESTOWN S'KLALLAM TRIBE

On behalf of the Jamestown S'Klallam Tribe, I would like to thank you for this opportunity to submit this written testimony on FY2015 Appropriations for the Department of Health and Human Services. The Federal budget for Tribal health programs and services should reflect the US Government's commitment to honor and uphold its Treaty and Trust obligations to American Indians and Alaska Natives. When Tribal Governments are empowered through Self-Governance with the flexibility and resources to provide quality healthcare to their citizens, these investments hold tremendous promise for not only Tribal communities but for the communities that surround them.

The Jamestown Family Health and Dental Clinics have demonstrated a real return on the Federal investment and reflect the tremendous potential Tribes have to not only reduce healthcare costs but to increase prevention and treatment services for their Tribal citizens.

TRIBAL SPECIFIC HEALTH APPROPRIATION PRIORITIES

1. Restore Sequestered Amounts/Exempt Indian Programs from Budget Reductions
2. Fully Fund Contract Support Costs – Separate Mandatory Appropriation
3. Budget Equity for Tribal Governments/Programs Accessible to Small Tribes
4. Medicare/Medicaid Reimbursement
5. Provide $30 Million for Part A Grants for Native Americans in the Older Americans Act – Title VI
6. Fund SAMHSA's Behavioral Health Tribal Prevention Grant Program at $50 million - make sure programs are accessible to small Tribes

NATIONAL HEALTH APPROPRIATION PRIORITIES

1. Definition of Indian
2. Fully Fund the Implementation of ACA Inclusive of the IHCIA
3. Self-Governance Promotes Efficiency and the Effective Use of Federal Funds (Title VI of the ISDEAA

REGIONAL / NATIONAL HEALTH APPROPRIATION PRIORITIES

Our Budget Request endorses the requests of The Northwest Portland Area Indian Health Board, Affiliated Tribes of Northwest Indians, the Indian Health Service Tribal Self-Governance Advisory Committee and the National Congress of American Indians and the National Indian Health Board.

TRIBAL SPECIFIC PRIORITIES

Restore Sequestered Amounts/Exempt Indian Programs from Budget Reductions
Despite the Federal trust obligation and the well documented and profound needs of Indian country, Tribal programs were subjected to sequestration and forced spending reductions. These budgetary reductions were devastating to our community and will drastically impede primary health care and disease prevention services for our Tribal citizens for years to come. Tribes should be afforded the same exemption from funding reductions that are in place for programs serving our nations populations with the highest need, such as, Social Security, Medicaid, Medicare, the Children's Health Insurance Program and the Veteran's Administration.

Fully Fund Contract Support Costs (CSC) as Required by Law
Adequate Contract Support Cost (CSC) funding assures that Tribes, under the authority of their Self-Governance compacts, have the resources necessary to administer and deliver the highest quality healthcare services to their members without sacrificing program services and funding. We urge you to consider turning CSC into a separate mandatory appropriation so that legally enforceable contractual obligations are not being funded at the expense of programmatic needs.

Budget Equity for Tribal Governments/Programs Accessible to Small Tribes
Budget inequity compromises our ability to adequately manage our health programs and services that we are providing on behalf of the Federal government. When Tribes receive an equitable level of resources, we can address the physical, spiritual and mental well-being of our Tribal communities in a culturally appropriate manner. There are often inconsistencies in how formulas are calculated and funding is distributed for Tribal health programs. In addition, Grant opportunities often contain criteria and processes that give States and other interest groups preferential opportunities for awards. Small Tribes, such as ours, are often further disadvantaged when it comes to securing these opportunities. It is critical that Tribes receive equitable resources and equitable access to funding opportunities that allow Tribes to continue to address Tribally-determined levels of health and wellness for our communities. Grants provided through the Administration for Children and Families (ACF) and the Substance Abuse and Mental Health Services Administration (SAMHSA) are critically important to our Tribe and we urge you to provide both equitable funding and opportunities for all Tribes within the confines of these programs.

Medicare/Medicaid Reimbursement
Federal funding for Medicaid/Medicare expansion is intended to reduce health disparities in our Tribal communities. Historic and persistent underfunding of the Indian healthcare system has limited the ability of Tribes to provide adequate health services that could prevent or reduce chronic health conditions in Native people. As a result, American Indians / Alaska Natives have a significantly worse health status compared to the rest of the nation.

Because we do not receive full federal funding to address our unmet healthcare needs, Jamestown has been forced to use innovative approaches in order to provide better healthcare

services to our Tribal citizens. Over 50% of our healthcare funding is Medicaid and Medicare and we use the revenue that is generated from these programs to provide essential health services to our Tribal citizens and their families. Any changes to the way we receive Medicare and Medicaid funding would negatively impact our ability to provide basic healthcare to our Tribal community and the surrounding non-Indian community. Our innovative approach to providing healthcare services is an effective and efficient use of the federal investment. It allows us to leverage the federal dollar to provide better health services to more of our Tribal citizens, reducing future healthcare costs by lessening the need for expensive chronic and emergency care.

$30 Million - Part A Grants to Native Americans under Title VI of the Older Americans Act

Programs under Title VI of the Older Americans Act are the primary funding vehicle for the provision of nutrition and other ancillary services to our Tribal Elders. Reducing isolation through community and cultural activities and ensuring our Elders receive proper nutrition and healthcare is a priority for our Tribe. Without the capacity to provide support services to our elders, our cultural traditions, and our language is at risk of being lost.

The Jamestown S'Klallam Elders Meal Delivery Program has been around for more than 20 years. The Older Americans Act provides much needed funds to keep this program working for our community. Jamestown has used federal funds to prepare and deliver well-balanced nutritional meals to our Elders that incorporate traditional foods, such as, elk and fish and use vegetables grown in our community garden. All of our elders are also given fresh fruit. These services are provided to all elders of Native heritage, and their spouses, within our service area.

$50 Million - Behavioral Health Tribal Prevention Program

American Indians and Alaska Natives have disproportionately higher rates of death related to alcohol and substance abuse and suicide. If funded, the Behavioral Health Tribal Prevention Grant will allow Tribes to provide behavioral health services that address substance abuse and suicide prevention and promote overall mental and emotional health. If funded, this would be the only grant program that is exclusively available for Tribes.

NATIONAL HEALTH PRIORITIES

Definition of Indian

The Administrations current interpretation of "Indian" in the Affordable Care Act (ACA) prevents certain IHS eligible persons from access to certain healthcare and services available to American Indians and Alaska Natives under the law. A technical amendment that uses the Center for Medicare and Medicaid definition of Indian will align the eligibility regulations and create consistency among all the Administrative agencies which will provide full access to healthcare for all American Indians and Alaska Natives.

Fully Fund the Implementation of ACA Inclusive of the IHCIA

The permanent reauthorization of the Indian Health Care Improvement Act (IHCIA) within the ACA is the most significant advancement in Federal health policy for Tribes in decades. The purpose of the IHCIA is to promote health care parity for Indian Tribes by addressing deficiencies in health status and resources within the Indian health system. Funding for the IHCIA is a top budget priority. Although the IHCIA provides the authority and, with it, the opportunity to provide essential health care to Tribal citizens, it did not provide the necessary funds to the IHS to carry out these new statutory obligations.

There are twenty three unfunded provisions in the Indian Health Care Improvement Act (IHCIA). Many of the provisions that remain unfunded would strengthen the Tribal health care workforce, provide greater access to behavioral health and support innovative initiatives for healthcare delivery to Tribal citizens. Funding these provisions is a necessary precursor to increase Tribal capacity, infrastructure and most importantly access to health care services. Significant federal investment is needed to achieve a fully funded Indian Health Service and now is the time to act on opportunities made possible in the newly expanded authorities granted under the Indian Health Care Improvement Act. Given the unique mission of the IHS as a direct health care provider fulfilling a federal trust responsibility, fully funding and implementing the ACA and IHCIA will elevate the health status and decrease the health disparities experienced by American Indians and Alaska Natives.

Self-Governance - An Efficient and Effective Use of Federal Funds (Title VI of the ISDEAA)

Self-Governance is the most successful policy in the history of Tribal – Federal relations and it inspires efficient and effective government spending. Through Self-Governance, Tribes are empowered, as sovereign nations, to exercise self-determination and to design facilities, manage programs and funds, and provide services that are responsive to the needs of our communities and Tribal citizens. Tribes participating in Self-Governance have become successful in the business of healthcare and perform several key roles, serving as, governments, employers, healthcare providers and patients.

Self-Governance Tribes have made every attempt to be innovative to operate successful health programs given the budget constraints and cuts Tribal programs have incurred the past two decades. For more than a decade we have made every effort to expand Self-Governance to other programs and our efforts to seek expansion of the program will continue until we achieve our goal. We request that this Committee recognizes the success of Self-Governance and encourage HHS to work with Tribes to make the most efficient and effective use of federal appropriations to fund Tribal programs.

Conclusion

Thank you for the opportunity to provide this important testimony. We respectfully request that these Budget Priorities be included in the Appropriations for the FY2015 Tribal Health Programs Budget.

Testimony in Support of the State Paid Leave Fund

Submitted to the U.S. House of Representatives Committee on Appropriations

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

Marilyn Watkins, Washington Work and Family Coalition

March 28, 2014

As the Chair of the Washington Work and Family Coalition, I respectfully urge the Committee on Appropriations to include the State Paid Leave Fund, administered through the Department of Labor, in the Fiscal Year 2015 Labor, Health and Human Services and Education bill. The bill should include the $105 million funding proposed in the President's budget. The State Paid Leave Fund would create a competitive federal grant fund designed to spur innovation among states interested in creating family and medical leave insurance (FMLI) programs, as well as those with established FMLI programs, and has the potential to help millions of American families, including thousands here in Washington State, maintain economic security.

For over a decade, the Washington Work and Family Coalition has brought together seniors, women, labor unions, health professionals, children's advocates, faith communities, low income workers, employers, and policy makers to ensure all workers have access to paid sick days and family and medical leave insurance. The Coalition has successfully led the fight for state-wide legislation that allows workers with paid leave to use it to care for sick family members, and that lays the foundation for a family and medical leave insurance program for all workers.

Currently, Washington has an unfunded paid leave law that would allow for up to five weeks of paid leave for new parents. Due to budgetary restraints resulting from the Great Recession, this program has never been implemented. The Coalition has continued to push for implementation, but has also supported newer legislation to expand and fund a comprehensive family and medical leave insurance program. With funding from the State Paid Leave Fund, family and medical leave insurance would finally become a reality for Washington's working families.

At some point in their working lives, almost all Americans will need to take time off to care for a new baby or adopted child, an ailing child or parent, or their own health. The Family and Medical Leave Act – the only federal law designed to help working people meet the dual demands of job and family – leaves out 40 percent of the workforce and guarantees only unpaid leave, which millions cannot afford to take. And only 12 percent of the U.S. workers currently have access to paid family leave through their employers. That means millions of workers who develop serious health conditions, have seriously ill family members or become parents are forced to choose between what is best for them and their families and income they need to cover basic expenses.

Family and medical leave insurance programs at the state level allow workers to pay a small portion of their wages each week for the guarantee that when they need it, they can receive a percentage of their wages while they have to take extended family or medical leave from work. These programs help working families stay afloat when they need time off to care for an ill family member, a new baby or their own health.

Three states – California, New Jersey and Rhode Island – have created family and medical leave insurance programs. Research has shown that paid leave programs

contribute to increased family financial stability and improved child well-being, better workforce outcomes for new parents, reductions in government public assistance expenditures, and cost-savings for businesses.

Our aging population also makes family and medical leave insurance imperative. Providing financial support for family members caring for aging loved ones promotes the health, independence, and well-being of seniors, while saving public resources.

That's why there is broad support among the business community for paid family and medical leave programs. Businesses understand it's good for their bottom line. Small business owners in Washington state are among the advocates for establishing a program in our state. California employers report that the program has had a neutral or positive effect on employee productivity, profitability, and turnover, and most employers coordinate their own benefits with the state's PFL program. A 2011 study of California's FMLI program estimated that it would save employers $89 million a year. A recent Rutgers study shows that New Jersey's FMLI program has saved businesses money by improving employee retention, decreasing turnover costs, and improving productivity.

A federal grant program would help states with one-time start-up costs to develop and implement successful family and medical leave insurance programs that are so needed across the country. Once these insurance programs are up and running they become self-sustaining. Without this federal support, the initial capital needed to design and launch these programs would continue to act as a roadblock, despite broad public support.

This fund would benefit both states considering a family leave and medical insurance program and states with an existing FMLI program. States with established FMLI programs could apply for grants to increase awareness about and utilization of the

program by conducting outreach to ensure eligible workers who have been paying into the program are accessing it when they need it. For many states considering programs, access to competitive federal grants that help defray the one-time costs of designing and launching these insurance programs would provide a compelling incentive to states to innovate. In the case of the SPLF, a modest investment at the federal level would translate to significant impact for millions of families' economic security.

Washington is actively advancing FMLI legislation, but there are immediate research needs that the SPLF could help fund. For example, Washington is exploring whether fully implementing family and medical leave insurance might result in cost savings to the state through better maternal and infant health, less reliance of new parents on public assistance, and more engagement of family members in senior care. If these bills become law, the fund could also help with the necessary start-up costs. The prospect of the SPLF promises an incentive for our state to implement legislation, knowing they can tap federal dollars to support one-time, start-up costs that would otherwise be prohibitive.

In sum, there is tremendous support across the country for creating a new State Paid Leave Fund. Nearly a dozen states, including Washington, could immediately benefit from federal funds made available through a competitive grant program. I urge you to pass a budget bill with $105 million allocated for the State Paid Leave Fund to help states like Washington with programs that benefit working families, businesses, and the local economy.

Signers:

American Association of University Women, Washington Chapter
Children's Alliance
Early Learning Action Alliance
Economic Opportunity Institute

Faith Action Network
Legal Voice
Main Street Alliance of Washington
Puget Sound Advocates for Retirement Action
SEIU Healthcare 1199NW
Senator Karen Keiser, 33rd Legislative District, Washington
Teamsters Joint Council 28
Teamsters Local Union No. 117
Washington State Labor Council, AFL-CIO
Washington Work and Family Coalition

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 170 public television licensees, we appreciate the opportunity to submit testimony for the record on the importance of federal funding for local public television stations and PBS. We urge the Subcommittee to support level funding of $445 million in two-year advance funding for the Corporation for Public Broadcasting (CPB) in FY 2017, and pre-sequester level funding of $27.3 million for the Ready To Learn program at the Department of Education in FY 2015.

Corporation for Public Broadcasting—FY 2017 Request: $445 million, two-year advance funded

Local stations and PBS are committed to serving the public good in education, public safety, creating a well-informed citizenry, preserving and promoting American history and culture, and other essential fields. Federal funding for CPB makes these services possible and is deserving of continued support. The overwhelming majority of Americans agree. In a bi-partisan Hart Research Associates / American Viewpoint poll, nearly 70 percent of American voters, including majorities of self-identifying Republicans, Independents, and Democrats support continued federal funding for public broadcasting. In addition, polls show that Americans consider PBS to be the second most appropriate expenditure of public funds, behind only military defense.

Over 70% of the federal funding for CPB goes directly to local stations, resulting in a nationwide system of locally owned and controlled, trusted, community-driven and community-responsive media entities that form an incredibly successful public-private partnership providing unique and essential local public services.

Education

Local public television stations are America's largest classroom, meeting their communities' lifelong education needs by providing the highest quality educational content and resources on multiple media platforms and in person. Public television's exceptional content, available to nearly every household in America, has helped more than 90 million pre-school age children get ready to learn and succeed in school. PBS, in partnership with local public television stations, has created PBS LearningMedia, an online portal where educators can access more than 35,000 standards-based, curriculum-aligned interactive digital learning objects created from public television content, as well as material from the Library of Congress, National Archives and other high-quality sources. More than 1.3 million teachers are registered to use PBS LearningMedia in K-12 classrooms serving millions of students throughout the country. In addition, twenty-eight thousand homeschoolers use PBS LearningMedia to enrich their curriculum in history, science, the arts and other subjects. Public television stations also operate virtual high schools that bring high-quality instruction in the most specialized fields to the most remote locations in our country.

Through the American Graduate Initiative, CPB and public media stations are working to confront the dropout crisis in America's high schools by providing resources and services to raise awareness, coordinate action with local community partners, and work directly with students, parents, teachers, mentors, volunteers and leaders to lower the drop-out rate in their respective communities. In addition, by operating one of the most comprehensive non-profit GED programs in the country, public television stations have helped hundreds of thousands of second-chance students and adult learners get their high-school equivalency certificates and prepare themselves for meaningful work in a competitive marketplace. Public television stations have made it a top priority to help retrain the American workforce, including veterans, by providing digital learning opportunities for those looking for training, licensing, continuing education credits and more.

Partners in Public Safety

Public broadcasting stations throughout the country are also leading innovators and irreplaceable partners to local public safety officials – working in communities with schools, businesses and stakeholders to provide real-time emergency support for local law officials in times of crisis. In many communities, public broadcasting stations are the last locally-owned and operated media outlets – serving as a critical public safety life line.

The nation's digital presidential alert and warning system depends on the backbone infrastructure of local public television stations to deliver critical national messages. This same digital infrastructure provides the backbone for emergency alert, public safety, first responder and homeland security services in many states and local communities. Stations are partnering with their local emergency responders to customize and utilize public television's infrastructure for public safety in a variety of critical ways: equipping police cars with school blueprints when a crisis arises, providing access to 24/7 camera feeds for a variety of security challenges, connecting public safety agencies in real time, and more. Local public television stations are also using their broadcast equipment to help send emergency alert text messages to cell phone subscribers through their providers – reaching citizens wherever they are, even when the power is out. Many local stations are serving as their states' primary Emergency Alert Service (EAS) hub for weather and AMBER alerts.

Supporting an Informed Citizenry

Public television strengthens the American democracy by providing citizens with access to the history, culture and civic affairs of their communities, their states and their country. Local public television stations serve as the "C-SPAN" of many state governments, providing the most remote corners of the country with access to the state legislative process, Governors' messages, court proceedings and more. As one of the only locally-owned and operated media remaining in America, public television provides more public affairs programming, local history, arts and culture, candidate debates, specialized agricultural news, and citizenship information of all kinds than anyone else in the media universe.

Public Broadcasting is a Smart Investment

All of this is made possible by the federal funding to CPB which amounts to an annual cost of about $1.35 per year for each American. On average, federal funding for CPB makes up approximately 15 percent of local television station's budgets. However, for many smaller and rural stations, federal funding represents more than 30-50 percent of their total budget. This funding is particularly important to rural stations that struggle to raise local funds from individual donors due to the smaller and often economically strained population base. At the same time it is often more costly to serve rural areas due to the topography and distances between communities. As a result, public broadcasters, with their commitment to universal service, are often the only local broadcaster serving rural communities. For all stations, federal funding is the "lifeblood" of public broadcasting, providing critical seed money to local stations that enables them to build additional support from state legislatures, private foundations and corporations, and "viewers like you."

Public broadcasting creates important economic activity while providing an essential educational and cultural service. For every federal dollar, local public media stations raise an additional six dollars in non-federal funding, providing a strong public-private partnership and an impressive 6 to 1 return on investment. In addition, public broadcasting supports approximately 20,000 jobs, with the vast majority in local public television and radio stations in hundreds of communities across America.

Two-Year Advance Funding

Two-year advance funding is essential to the mission of public broadcasting. This longstanding practice, proposed by President Ford and embraced by Congress in 1976, establishes a firewall insulating programming decisions from political interference, enables the leveraging of funds to ensure a successful public-private partnership, and provides stations with the necessary lead time to plan in-depth programming and curriculum coordination with educational institutions

Public television's history of editorial independence has been rewarded in unprecedented levels of public trust—for the eleventh consecutive year, the American people have ranked PBS as one of the most trusted national institutions. Advance funding and the firewall it provides between the development of content and extraneous interference and control is vital to maintaining this credibility among the American public.

In addition, local public broadcasting stations leverage the two-year advance funding to raise state, local and private funds, ensuring the continuation of this strong public-private partnership. These federal funds act as essential seed money for fundraising efforts at every station, no matter its size, and since many state legislatures are part-time institutions that budget State funds on a two-year cycle and relate state funding to federal funding, advance federal funding is essential to the success of this unique partnership

Finally, the two-year advance funding mechanism also gives stations and producers the critical lead time needed to partner with local community organizations and plan and produce high-quality programs. The signature series that demonstrate the depth and breadth of public television, like Ken Burns's *The Civil*

War, take several years to produce. In addition, two-year advance funding is essential to the creation of local programming over multiple fiscal years as stations convene the community to identify needs, recruit partners, conduct research, develop content and deliver services.

Ready To Learn—FY 2015 Request: $27.3 million (Department of Education)

The Ready To Learn (RTL) competitive grant program uses the power of public television's on-air, online, mobile, and on-the-ground educational content to build the literacy and STEM skills of children between the ages of two and eight, especially those from low-income families. Through their RTL grant, CPB and PBS are delivering evidence-based, innovative, high-quality transmedia content to improve the math and literacy skills of high-need children via broadcast television, the Internet, mobile and other dynamic new technologies. CPB and PBS, in partnership with local stations, have been able to ensure that the kids and families that are most in need have access to these groundbreaking and proven effective educational resources. In addition to the content, CPB and PBS are creating new tools like a sophisticated progress tracking system that gives parents the means to measure student progress, in real time.

Results

RTL is rigorously evaluated for its appeal and efficacy so the program can continue to offer America's youngest citizens the tools they need to succeed in school and in life. Studies show that RTL content has a significant and positive effect on the educational lives of children who use it. Highlights of recent studies show that: use of PBS KIDS content and games by low-income parents and their preschool children improves math learning and helps prepare children for entry into kindergarten[1]; use of RTL content has been associated with a 29 percent improvement in reading ability in children grades K-2[2]; and parents who used RTL math resources in the home became considerably more involved in supporting their children's learning outcomes[3]. In combination, RTL games, activities and videos provide early learners with the critical math and literacy skills needed to succeed in school, and in the process, help level the academic playing field.

An Excellent Investment

In addition to being research-based and teacher tested, the RTL Television program also provides excellent value for our federal dollars. In the last five-year grant round, public broadcasting leveraged an additional

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[1] McCarthy, B., Li, L., Schneider, S., Sexton, U., & Tiu, M. (2013). PBS KIDS Mathematics Transmedia Suites in Preschool Homes and Communities. A Report to the CPB-PBS Ready to Learn Initiative. Redwood City, CA: WestEd. McCarthy, B., Li, L., Tiu, M. (2012). PBS KIDS Mathematics Transmedia Suites in Preschool Homes. Redwood City, CA: WestEd

[2] Public Broadcasting Service (2012). KBTC Ready To Learn Initiative 2012 Summary Report, pp. 15,16.

[3] McCarthy, B., Li, L., Schneider, S., Sexton, U., & Tiu, M. (2013). PBS KIDS Mathematics Transmedia Suites in Preschool Homes and Communities. A Report to the CPB-PBS Ready to Learn Initiative. Redwood City, CA: WestEd. McCarthy, B., Li, L., Tiu, M. (2012). PBS KIDS Mathematics Transmedia Suites in Preschool Homes. Redwood City, CA: WestEd

$50 million in funding to augment the $73 million investment by the Department of Education for content production. Without the investment of the federal government, this supplemental funding would likely end.

The Dangers of Consolidation

The President's FY 2015 budget proposes consolidating RTL into a larger grant program. APTS and PBS oppose this proposal as it would abandon the unique national-local partnership that has resulted in RTL's ground-breaking educational impact on kids nationwide, particularly those with limited access to other educational resources. The current model effectively uses an economy of scale to create high-quality television and online content at the national level and then distribute it through local stations who can tailor outreach to the specific needs of their communities. This model allows PBS and local stations to annually reach 80 percent of America's children ages 2 to 8 through television and another 13 million per month online and on mobile apps. The national-local partnership has made RTL tremendously efficient and effective and consolidation or elimination of the program would severely affect the ability of local stations to respond to their communities' educational needs, eliminating the critical resources provided by this program for children, parents and teachers.

RTL symbolizes the mission of public media and is a successful public-private partnership that leverages federal funds to create the most appealing and impactful children's educational content that is supplemented by online and on-the-ground resources. Without the RTL program, millions of families would lose access to this incredible high-quality education content, especially the low-income and underserved households that are a particular focus of this program.

Conclusion

Americans across the political spectrum rely on public broadcasting -- on television, on the radio, online, and in the classroom – because we provide essential education, public safety, and informed citizenry services that are not available anywhere else. And none of this would be possible without the federal investment in public broadcasting. A 2007 GAO report concluded that these federal Community Service Grants are an irreplaceable source of revenue for public broadcasting, and a 2012 study requested by this Subcommittee and conducted by an independent third party for CPB came to the same conclusion as the GAO: federal funding for public broadcasting is irreplaceable.

For all of these reasons we request that Congress continue its commitment to the highly successful, hugely popular public-private partnership that is public broadcasting by providing level funding of $445 million in FY 2017 for the two-year advance of the Corporation for Public Broadcasting and pre-sequester level funding of $27.3 million in FY 2015 for the stand alone Ready To Learn Program.

Testimony of Stephen DeWitt

Deputy Executive Director

Association for Career and Technical Education

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

Committee on Appropriations

U.S. House of Representatives

Mach 28, 2014

Chairman Kingston, Ranking Member DeLauro and members of the subcommittee, on behalf of the Association for Career and Technical Education (ACTE), I would like to urge you to help support career and technical education (CTE) through a strong federal investment in the Carl D. Perkins Career and Technical Education Act (Perkins) for Fiscal Year (FY) 2015 (administered by U.S. Department of Education Office of Career, Technical, and Adult Education). The passage of the Bipartisan Budget Act and subsequent Consolidated Appropriations Act of 2014 helped to alleviate some of the harmful sequestration cuts that have impacted important career education and workforce training programs, but more needs to be done to support our high schools, technical centers, community colleges and millions of CTE students nationwide. To

that end, I respectfully request that the subcommittee restore Perkins funding to $$1.131 billion, equivalent to the pre-sequestration total funding level, as part of the FY 2015 Labor, Health and Human Services, and Education appropriations bill. We would also request that the subcommittee work to restore the $103 million cut to CTE state funding that resulted from the elimination of funding for the Tech Prep program in FY 2011.

Perkins is the principal source of federal support for CTE programs at secondary and postsecondary institutions across the county. This federal investment is crucial to ensuring that students have the academic, technical and employability skills that are needed for careers in expanding fields like engineering, information technology, advanced manufacturing and health care. Perkins-funded CTE programs are working with business and industry partners to help fill positions that are available today, while preparing a qualified workforce for the careers of tomorrow. In a rapidly changing job market, CTE provides students with transferable skills that ensure they are college-and career-ready, while offering retraining opportunities to many adult or dislocated workers.

Perkins produces a strong return on the federal investment. Students enrolled in CTE programs are more engaged, perform better academically and graduate at higher rates. CTE supports the development of an educated and highly skilled workforce that

provides a direct benefit to employers, while strengthening the economy through increased productivity and innovation.

Perkins is the foundational support for CTE program improvement that is essential to moving our economy forward. However, funding has not kept pace with the demand for high-quality programs. Perkins funding is more than $140 million lower than it was in FY 2010, with more than 20 states currently receiving allocations at 1998 levels. The erosion of Perkins funds comes at a time when CTE programs are experiencing new attention and growth. A recent survey by the Education Development Center, Inc. found that approximately 73 percent of education providers reported flat or declining CTE budgets over the past five years, with 62 percent of programs surveyed reporting anticipated enrollment growth next year. Perkins funding is an essential component in allowing education providers to build the capacity necessary to serve the 12 million secondary, postsecondary and adult students nationwide.

I would also like to express our concerns about the Obama Administration's budget request for FY 2015, which provides inadequate funding for CTE programs. The budget proposes to level fund the Perkins CTE State Grant program at $1.118 billion ($5 million below the pre-sequestration level), with CTE National Programs frozen at $7.4 million. We also disagree with the Administration's proposal for a $100 million set aside from

CTE State Grant funding to create a new competitive innovation fund. While we support the fostering of innovative practices in CTE, this proposal would further reduce the formula funding available to states. The Administration should work with Congress to develop a CTE innovation program through the reauthorization of the Perkins Act that does not rely on syphoning funds from CTE state grants. It is the position of ACTE that current funding for education and job training is better directed to proven, existing programs that provide for the equitable distribution of federal resources.

A bipartisan coalition of Members of Congress will soon submit a letter to this subcommittee expressing support for funding CTE. They will request that total Perkins funding be restored to at least $1.131 billion in FY 2015 Labor, Health and Human Services, and Education appropriations bill. ACTE strongly supports this effort and we reaffirm the message that CTE works to ensure that students have the academic and technical skills necessary for true career readiness—and that Perkins funding is a key component to student success.

Thank you for your continued leadership and for your thoughtful consideration during the appropriations process. We look forward to working with the subcommittee in a bipartisan fashion to make building our investment in CTE a top priority.

Written Testimony of Dr. Judith A. Salerno
President and Chief Executive Officer
Susan G. Komen

Submitted to the House Appropriations Subcommittee
on Labor, Health and Human Services, Education, and Related Agencies
Regarding FY2015 Funding for the
National Breast and Cervical Cancer Early Detection Program and
Cancer Research at the National Institutes of Health

March 28, 2014

On behalf of Susan G. Komen®, I appreciate the opportunity to submit written testimony regarding the need for increased federal funding for breast cancer early detection programs and cancer research. **Specifically, we call on you to increase funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), funded through the Centers for Disease Control and Prevention (CDC), to $275 million and for the National Institutes of Health (NIH) to $32 billion in FY15, including $5.26 billion for the National Cancer Institute (NCI).**

Komen is the world's largest grassroots network of breast cancer survivors and advocates fighting to save lives, empower people, ensure quality care for all, and energize science to find the cures. With our network of local Affiliates across the U.S. and the 2.9 million breast cancer survivors we represent, we have long considered ourselves key partners with the federal government in the fight against breast cancer. Since 1983, we have invested more than $2.5 billion for breast cancer research and life-saving community programs across the country.

While I recognize the difficult task in balancing competing budget priorities in the current fiscal climate, the only way to eradicate breast cancer is through a renewed investment and commitment to discovering and delivering the cures and improved access to affordable, quality and timely breast health screening and treatment services.

National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

We call on Congress to increase funding for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), funded through the Centers for Disease Control and Prevention (CDC), to $275 million in FY15.

NBCCEDP provides lifesaving, free or low-cost breast cancer screenings, diagnostic services, and follow-up services to low-income, uninsured and underinsured women. Since its inception, NBCCEDP has provided over 11 million screening exams to more than 4.4 million women, detecting more than 594,000 breast cancers, 3,300 cervical cancers and 158,000 premalignant cervical lesions.[1] Despite the critical services this program provides, at current funding levels, NBCCEDP can serve less than one-third of the estimated number of eligible women needing care.[2]

Lack of insurance is an impediment to women receiving an annual mammogram which can lead to early detection and effective treatment for breast cancer.[3] While the Affordable Care Act increases access to mammography coverage for many women, millions of low-income women will remain uninsured and in need of the breast and cervical cancer screenings provided by the NBCCEDP. Without these services, many of these women would be forced to delay or forego screenings, leading to later stage diagnoses, which are deadlier and more costly to treat. Breast cancer can be up to five times more expensive to treat when it has spread to other parts of the body.[4]

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[1] *Division of Cancer Prevention and Control*

[2] *Levy AR, Bruen BK, Ku L. Health Care Reform and Women's Insurance Coverage for Breast and Cervical Cancer Screening. Prev Chronic Dis 2012;9:120069.*

3 ACS Cancer Prevention and Early Detection Facts and Figures 2013- http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-037535.pdf

[4] *Cost of Breast Cancer Treatment in Medicaid- Med Care. 2011 Jan;49(1):89-95. doi: 10.1097/MLR.0b013e3181f81c32.*

Even with health insurance, many women still face substantial barriers to obtaining health services because of lack of health literacy, geographic isolation and language barriers. For these women, NBCCEDP fills a critical gap by removing barriers to care.

National Institutes of Health (NIH)

We urge you to increase funding for the National Institutes of Health (NIH) to $32 billion in FY15, including $5.26 billion for the National Cancer Institute (NCI), in order to restore funding to inflation-adjusted, pre-sequestration levels. Cancer is an expensive disease--the most costly to our nation in terms of direct medical costs and lost productivity due to premature deaths and disability-- making research which will accelerate cures and improve treatment a sound investment. Federal funding must keep pace with biomedical inflation as we stand on the threshold of life-saving discoveries in the biomedical sciences.

This investment in research will not only protect Americans against disease and illness, but will serve as one of our nation's primary paths to innovation, global competitiveness, and economic growth. As other nations aggressively invest in research and development, the U.S. is losing ground. We stand to lose the young scientists, high quality jobs, industries and private-sector capital that have made America a global leader.[5] Studies show each dollar in NIH funding generates more than twice as much in new business activity, and NIH grants and contracts created and supported more than 400,000 jobs across the country in 2013.

Our nation's investment in biomedical research has helped drive progress against cancer, furthered our understanding of disease mechanisms and spurred the translation of scientific discoveries into new and better ways to prevent, detect, diagnose, and treat cancer. We are

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[5] Research!America (Www.researchamerica.org)

poised to apply this new knowledge to make significant strides in saving lives. As U.S. population ages, the number of new cancer cases in the United States is projected to increase by as much as 42 percent, 2.3 million new cases annually, by 2025.[6] We are facing a crisis in cancer care.

Despite these staggering statistics, cancer research funding at the NCI as a share of the NIH budget has declined. In the late 1990s, NCI's budget made up nearly 19 percent of the NIH budget. Today, NCI accounts for approximately 16 percent. In real dollars, this decline means that NCI's funding has been reduced by $680 million below what it would have received in FY14 if its share of NIH's total budget had been maintained.[7] It is imperative that our nation's investment in cancer research remains a priority, and that funding for NIH increases.

On behalf of the many Americans who are suffering with cancer, I ask that you consider our requests for increased support for the NBCCEDP and the NIH in FY 2015. Susan G. Komen stands ready to serve as a national resource for Congress and for all Americans on breast health issues.

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[6] AACR Cancer Progress Report 2013 (http://cancerprogressreport.org/2013/Documents/2013_AACR_CPR_FINAL.pdf)

[7] One Voice Against Cancer (www.ovaconline.org)

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NATIONAL CONGRESS OF AMERICAN INDIANS

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

March 28, 2014

Testimony: Department of Labor and Corporation for Public Broadcasting

INTRODUCTION

The National Congress of American Indians (NCAI) is the largest and oldest representative organization of American Indian and Alaska Native tribal governments. NCAI represents the broad interests of tribes and their citizens to advance, and promote the advancement, of tribal Sovereignty and Self-Determination. NCAI respectfully submits this testimony on the Corporation for Public Broadcasting (CPB) and programs in the Department of Labor.

Department of Labor

Fund the Department of Labor's Indian and Native American Program (INAP) at a minimum of $60.5 million. Fund the Native American Employment and Training Council at $125,000 from non-INAP resources. In order to reduce the education and employment disparity between Native people and other groups, a concentrated effort is required that provides tailored and sufficient assistance to enhance education and employment opportunities, to create pathways to careers and skilled employment, and to secure a place for Native people within the nation's middle class. The Workforce Investment Act (WIA) Section 166 program (INAP) serves the training and employment needs of over 38,000 American Indians and Alaska Natives via a network of 175 grantees through the Comprehensive Service Program (Adult) and Supplemental Youth Service Program (Youth), and the Indian Employment and Training and Related

Services Demonstration Act of 1992, Public Law 102-477. Furthermore, the number of American Indians and Alaska Natives served through WIA does not fully capture its impact in Indian Country, as many more are served by grantees that leverage WIA funding, along with other similar federally funded employment and training programs, through PL 102-477.

There has been a trend of decreasing funds for INAP, and a failure to appropriate at the statutory minimum level of $55 million. These decreases in funding are detrimental and hamper progress in Indian Country's labor situation. According to the Census, the average unemployment rate on reservations dropped more than 3 percentage points since 2000[1], but more still needs to be done as American Indians and Alaska Natives still lag significantly behind. With the average unemployment rate in Indian Country cited up to 17 percent[2] and an average joblessness rate of approximately 50 percent[3], INAP is vital to helping reverse these trends.

Further, because INAP is the only federal employment and job training program that serves American Indians and Alaska Natives who reside both on and off reservations, it is imperative that its funding is preserved. For Native citizens living on remote reservations or in Alaska Native villages, it can be difficult to access the state and local workforce systems. In these areas, INAP can be the lone employment and training provider. Since 2003, WIA has been up for reauthorization; and over this ten-year period, WIA has not accounted for the population growth of tribal communities, nor the economic environment that has drastically changed. WIA authorizes the INAP to be funded at "not less than $55 million," but Section 166 is currently being funded at approximately $46 million. WIA also authorizes the Native American Employment and Training Council to advise the Secretary on the operation and administration of INAP, but it uses funds that are intended for INAP grantees. Since the current INAP funding is

[1] US Census Bureau. Census 2000 Summary File 4, 2006-2010, 2009-2011 American Community Survey
[2] U.S. Census. 2011 American Community Survey
[3] U.S. Department of Interior. Bureau of Indian Affairs. 2005 American Indian Labor Force Report

already below $55 million, the Secretary should use other streams of funding to support its advisory council. Without an increase in funding, not enough tribes are able to benefit from the support and training activities for employment opportunities in Indian Country.

Restore the YouthBuild Program funding to a minimum of $102.5 million, restore the rural and tribal set-aside in the YouthBuild program, and reinstate a dedicated 10 percent rural and tribal set-aside of at least $10.25 million. The YouthBuild program is a workforce development program that provides significant academic and occupational skills training and leadership development to youth ages 16-24, and engages approximately 10,000 youth annually. YouthBuild provides students seeking a GED or high school diploma an innovative alternative education program through personalized instruction, while simultaneously developing skills that allow them to be competitive when they enter the job market.

YouthBuild reports that since it was established in 1992 as a federal program, 120,000 YouthBuild students have built 22,000 units of affordable housing in low-income communities in 46 states and the District of Columbia. In 2007, when the program was transferred from the Department of Housing and Urban Development to the Department of Labor, the 10 percent set-aside for rural and tribal programs was eliminated. Additionally, YouthBuild regularly has to turn away thousands of people because of inadequate funds.

The YouthBuild program recruits youth who have been adjudicated, aged out of foster care, dropped out of high school, or are otherwise at risk of not having access to workforce training. According to YouthBuild, in 2010, 4,252 youth participated in the program and had a completion rate of 78 percent, and 60 percent of those who completed the program were placed in jobs or further education.[4] There are a number of tribal YouthBuild programs in several states, and Native Americans make up roughly four percent of YouthBuild participants. With the recent

[4] See youthbuild.org/research.

reduction in tribal YouthBuild programs, high unemployment rates, serious housing challenges in Indian Country, and the growing Native youth population (42 percent of American Indian/Alaska Native population is under 25 years old[5]), it is critical that the 10 percent rural and tribal set- aside be restored.

Corporation for Public Broadcasting

In the CPB, NCAI supports an advanced FY 2016 appropriation of $5 million for American Indian and Alaska Native radio stations. This $5 million appropriation would come out of the FY 2015 advanced appropriation of $445 million for the overall CPB budget. This is the same budget amount enacted for FY 2014 and requested for FY 2015.

For more than 30 years, decisions on the amount of federal support for public broadcasting have been made two years ahead of the fiscal year in which the funding is allocated. Since 1976, CPB's two-year advance appropriation has served as a Congressional strategy to protect public media from any immediate political pressure. Community Service Grants (CSGs) account for approximately 70 percent of CPB's appropriation, which directly funds 1,300 local public television and radio stations including 35 Native radio stations.

In Indian Country, Native radio stations are essential to the tribal communities they serve since they are often the first source of emergency reporting and information. Public broadcasters use datacast technology for homeland security, public alert and warning systems, and public safety purposes. In Oklahoma, KCNP Chickasaw radio provided real time weather reports that saved lives during the 2013 tornado season. In Arizona, KUYI Hopi radio provides "House Calls," a health call-in show that connects listeners with a local doctor on questions about hanta virus, diabetes, HIV, and other local

[5] US Census Bureau, 2010 Census, Summary File 1.

health issues. In Alaska, KNBA covers news from Alaska Native villages about climate change refugees, language revitalization, and other hyper local stories important and relevant to Alaska Native communities. Often, the only place where Native stories and issues are heard is on Native radio stations.

Local public media stations and their employees have experienced significant reductions through cuts to other federal programs that benefit public media. The elimination of CPB's Digital appropriation and the Public Telecommunications Facilities Program coupled with cuts to programs at the Departments of Education and Agriculture represent a $57.5 million, or 7.3 percent, funding cut between FY 2010 and FY 2012. These cuts come at a time when stations are struggling to maintain service to their communities in the face of shrinking nonfederal revenues – a $239 million, or 10.8 percent, drop between FY 2008 and FY 2011.

CPB also funds the essential system-wide station support services provided by Native Public Media, Inc., and content production and satellite programming distribution by Koahnic Broadcast Corporation. Access to these funds allows Native Public Media, Inc., to ensure that Native radio stations stay on the air by maintaining compliance with FCC and other federal rules and regulations, and by providing the training and support Native broadcasters need.

Native public radio stations still exist as one of the primary sources of public information on tribal lands, and represent cornerstones of tribal efforts for information dissemination. Much of Indian Country remains disconnected from vital telecommunications services, radio should not be counted among them. Radio has always existed as a key component of public information and 55 tribal radio stations among this country's 566 federally recognized tribes illustrates the need for these services in Indian Country.

Statement of Sandra K. Jackson
Home Health Aide
and
Member of Arkansas State Council 38
of the
American Federation of State, County, and Municipal Employees, AFL-CIO
for the
House Appropriations' Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
on
FY 2015 Appropriations

My name is Sandra K. Jackson. I have been a home health aide in Marianna, Arkansas, for seven years. Programs like Arkansas' ElderChoices and IndependentChoices provide services that make it possible for seniors and other people with long-term disabilities to remain in their homes or live with their families so they do not have to go into an institution. Everyday I and my fellow home health aides and personal care attendants see how vital our work is to the independence and dignity of those we serve and the support we give to their families. And, we know how vital it is for Medicaid and other programs in the Administration for Community Living to support this work.

Without federal spending for homemaking services, respite care, and personal care services, many Arkansas families would not be able to care for their loved ones with dementia or other chronic conditions at home. These seniors served our nation, toiled for decades, reared families, and made our communities a good place to live and work. Without increased federal funds to support in-home care services, these elder members of our communities will suffer because they will not be able to remain in the comfort of their own homes.

I urge you to oppose any proposals that would limit federal support for in-home care services. Instead, I ask that you increase federal aid for states to invest in home care and

homemaking services, and respite care for family members caring for those with dementia and other disabling conditions in programs like the federal Administration on Aging's Home and Community-Based Supportive Services (HCBSS). And, I ask that you increase federal dollars to help states invest in the home care workforce.

HCBSS, combined with Medicaid, helps states serve seniors holistically. This funding allows for a combination of supports to be tailored to the needs of the individual. It is this mixture of services that makes it possible for seniors to remain in their own homes instead of entering nursing homes. In FY 2012, HCBSS provided nearly 29 million hours of assistance to seniors unable to perform basic tasks such as eating, dressing, and bathing, or needed chores such as shopping, light housework or laundry.

But the demand for in-home services is larger than what we can do under current federal funding. Some 154,866 Arkansas seniors live at home but have serious problems walking. This year it is projected that 52,000 Arkansas seniors will have Alzheimer's. But only 831 caregivers received respite help under the HCBSS program, according to HHS. And only 621 seniors received personal care services. Some 150 received homemaker services and 350 received help with chores. Federal funds for this program have not increased in years. I ask that you increase the funds to meet the desperate need.

I see how federal support for state programs for in-home services such as personal care, chores, and homemaker assistance make a real difference in the lives of seniors and their families. I currently help Mrs. D. five days a week for five hours each day. She is in her 70s. Mrs. D. has Alzheimer's disease, diabetes and other chronic conditions. In the two years that I have cared for her I have seen her decline. When I first came to help her she was walking

around, could dress herself and talk. She loved to laugh and dance. When I said, "Let's dance," she would move her arms as best she could like a butterfly. She still likes to laugh but she needs my help to eat, transfer to the wheelchair and transfer to bed. I am grateful that I make a difference in her life and that I am helping someone who needs it.

I also help Mrs. P. twice a week for two hours each day. She is in her 80s and has a very hard time getting around, but she is sharp as a tack. Because of a number of federal programs her family is able to patch together the care she needs.

There are more Mrs. D's and Mrs. P's in Arkansas and around the nation that would like to continue staying in their home but cannot because federal funds for homemaking, personal care and respite care are limited.

On behalf of Arkansas State Council 38 of AFSCME, I urge you to increase federal dollars spent in states on in-home care services for seniors and individuals with disabilities. I also urge you to increase federal funds so that states can invest in their home care workforce.

Statement by United for Medical Research on
FY 2015 Appropriations for the National Institutes of Health
submitted for the record by Carrie Wolinetz, Ph.D to the
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States House of Representatives

United for Medical Research (UMR) represents leading research institutions, patient and health advocates and private industry, joined together to seek steady increases in federal funding for the National Institutes of Health (NIH). We appreciate the opportunity to express our strong support for continuing our nation's commitment to biomedical research, so that we may remain the world leader in the life sciences. UMR recognizes that this is a time of difficult choices and fiscal constraint. However, we urge Congress to ensure NIH remains a priority, as an economic driver and jobs creator, an irreplaceable federal funder of basic research, and the source for extraordinary improvements in our health, longevity, and quality of life; we request $32 billion for NIH in the FY2015 Labor/Health and Human Services/Education and Related Agencies Appropriations bill.

NIH Research is Critical to Private Sector Innovation

A steady stream of medical advances, from new drugs and devices to improved diagnostics and cutting edge technologies, are founded in federally funded research discoveries. The biomedical research pipeline is a partnership between the 325,000 scientists funded by NIH, performing research at 3,000 institutions in all fifty states, and the private sector, which provides the products to support research discovery and brings research breakthroughs to fruition and into the marketplace. As Senator Richard Durbin recently asserted, "In the last two centuries, U.S. government support for scientific research has helped split the atom, defeat polio, conquer space,

create the internet, map the human genome, and much more. No nation has ever made such a significant investment in science, and no nation's scientists have ever done more to improve the quality of life on Earth."

NIH funds the highest-quality science and trains the next generation of medical researchers, ensuring that the pipeline of knowledge and talent does not run dry. The private sector's ability to maintain the rate of medical advancements, create and sustain high-wage jobs, and spur nationwide and regional economic activity depends on a sustained commitment to NIH. Unfortunately, in recent years, we have seen that commitment wane, and after a decade of budgets that have failed to keep pace with biomedical inflation and a $1.6 billion cut due to sequestration, NIH's loss of purchasing power is alarming. NIH Director Dr. Francis Collins recently underscored this point when he said, "NIH is the largest supporter of biomedical research in the world, but we are losing our edge. Since 2003, we've seen a steady decline in support, down to about 25 percent below where we were 10 years ago in terms of our power to fund research."

NIH as an Economic Engine

"Growing and sustaining a viable, long-term innovation eco-system is the smart choice and the only choice that makes sense for patients and for our national economy," noted John Castellani, President and CEO of PhRMA. NIH-supported research triggers private investment and significantly contributes to job growth and the overall strength of the U.S. in the global healthcare market. A 2012 report by UMR entitled *"NIH's Role in Sustaining The U.S. Economy"* shows that NIH funding directly and indirectly supported more than 432,000 jobs in

2011 alone and generated more than $62.1 billion in new economic activity. Using the Department of Commerce's RIMS II model, the analysis detailed the output and employment effects of 2011 NIH extramural research funding by state, calculating the number of jobs supported in each state by NIH funding. NIH funding generated the greatest number of jobs in California (63,196), Massachusetts (34,598), New York (33,193), Texas (25,878) and Maryland (24,557). In Georgia, NIH funding generated almost 11,000 jobs, and in Connecticut more than 6,500 jobs. Further, NIH funding supported more than 10,000 jobs in the following states: Pennsylvania, North Carolina, Washington, Illinois, Ohio, Florida, and Michigan. As Congressman Jack Kingston (R-GA), Chair of the Labor/Health and Human Services/Education and Related Agencies testified at a recent hearing, "NIH's support for extramural basic research provides the 'seed corn' for the private sector to create new, innovative preventable digital medicine."

The data housed in UMR's report clearly shows NIH's vital role in fueling economic growth in the health and life sciences industry. However, it also showed that the lack of sustained investment in the agency is beginning to have an impact. The decrease in NIH funding between 2010 and 2011, which was in part attributable to the end of supplementary funding by the American Recovery and Reinvestment Act, forecasted a decrease of approximately 55,000 jobs nationwide. This coupled with the $1.6 billion cut in funding due to sequestration has had real and lasting affect on jobs and research. As the data clearly shows, there is an urgent need to re-prioritize our support for biomedical research and this critical job sector by providing NIH with increased funding to counteract the affects of a budget that for the last decade has not kept pace with inflation and blunt the catastrophic impact of sequestration.

NIH Provides Hopes to Millions

Although its importance to the nation's economy is remarkable, we must not forget NIH's primary mission: to improve the health of the nation. NIH has been tremendously successful in improving human health and its accomplishments are numerous and well documented: a nearly 70 percent reduction in the death rate for coronary heart disease and stroke; advances in HIV/AIDS treatment that put an AIDS-free generation within reach; nearly 1 million lives saved due to decreases in cancer death rates over the past decade; and steady increases in life expectancy. Moreover, as our understanding of the human genome grows at an exponential rate, we have entered an era of personalized medicine where intervention on an individualized level is beginning to generate story after story of children and adults whose lives have been saved through cutting-edge research advances. These human stories of triumph over disease and scientific opportunity serve to provide hope to millions of patients whose diseases and conditions are still waiting for the next generation of treatment or cure.

Looming Threats: Global Competition and Sequestration

"Investing in research has huge paybacks, paybacks in improving the human condition and paybacks in reducing health costs as you get new tools," noted Bill Gates, Microsoft founder and Co-Chair of the Bill and Melinda Gates Foundation, when he visited NIH last year. Indeed, Congress' wisdom in investing federal dollars in NIH has yielded phenomenal dividends and made the U.S. the undisputed world leader in life science innovation. However, ever-shrinking budgets have made it difficult to maintain that leadership. Other nations are following in our footsteps to fuel their own biomedical research enterprises, even as we take a step back. China, India, the European Union, and Russia have all declared their intentions to increase their research

investment, despite the fiscal challenges presented by the global economy. "From 2007 to 2012, countries average annual investment in biomedical R&D increased 33 percent in China, 12 percent in South Korea, 10 percent in Singapore and it fell by 2 percent in the United States" Congresswoman Rosa DeLauro (D-CT), Ranking Member of the Labor/Health and Human Services/Education and Related Agencies Appropriations Subcommittee recently said. Losing our competitive edge in biomedical research is a clear and present danger to the crucial economic contributions of our life sciences innovation ecosystem.

NIH Should Remain a U.S. Priority

John Lechleiter, the CEO and chairman Eli Lilly & Co., once stated, "There's no better investment that we can make than in biomedical research and in our health. This is not something that we're trying to steal away from someone else... America leads the world." We could not agree more. While we appreciate the Administration's attempt to stymie some of the effect of sequestration on biomedical research, at this critical moment in our nation's history, increased investments in biosciences through the only federal agency specifically designed for this purpose —NIH — makes more sense than ever. For our economy, for our position as a world leader, for the health of our citizens, UMR respectfully requests Congress continue to capitalize on scientific opportunity by providing $32 billion for NIH in the FY2015 Labor/Health and Human Services/Education and Related Agencies Appropriations bill.

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House Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies

March 28, 2014

Testimony on Department of Education Programs

INTRODUCTION

The National Congress of American Indians (NCAI) is the oldest and largest American Indian organization in the United States. Tribal leaders created NCAI in 1944 as a response to termination and assimilation policies that threatened the existence of American Indian and Alaska Native tribes. Since then, NCAI has fought to preserve the treaty rights and sovereign status of tribal governments, while also ensuring that Native people may fully participate in the political system. As the most representative organization of American Indian tribes, NCAI serves the broad interests of tribal governments across the nation.

Investing in the education of American Indian and Alaska Native students is not only one most of the most important cornerstones of the federal trust responsibility to tribes, but is also critical strategy for creating jobs and securing the nation's future prosperity in today's challenging economic climate. President Obama has repeatedly stressed time and again that improving American education is an "economic imperative," and for tribes, the stakes are just as high, if not higher. Education provides tribal economies with a more highly-skilled workforce while also directly spurring economic development and job creation. The profound value of education for Native nations extends beyond just economics, however. Education drives personal advancement and wellness, which in turn improves social welfare and empowers communities—elements that are essential to maintaining tribes' cultural vitality and to protecting and advancing tribal sovereignty.

Despite the enormous potential of education for transforming tribal communities, Native education is in a state of emergency. American Indian and Alaska Native students lag far behind their peers on every educational indicator, from academic achievement to high school and college graduation rates. For example, in 2011, only 18 percent of Native fourth graders and 22 percent of Native eighth graders scored proficient or advanced in reading, and only 22 percent of Native fourth graders and 17 percent of Native eighth graders scored proficient or advanced in math.[i] The crisis of Indian education is perhaps most apparent in the Native high school dropout rate, which is not only one of the highest in the country, but is also above 50 percent in many of the states with high Native populations.[ii]

To address this urgent situation and provide tribal nations with the critical foundation for economic success, the federal government must live up to its trust responsibility by providing adequate support for Native education. The requests below detail the minimum appropriations needed to maintain a system that is struggling and underfunded. NCAI also fully supports the recommendations of the American Indian Higher Education Consortium for tribal colleges.

Title I, Part A Local Education Agency Grants - Provide $25 billion for Title I, Part A.

Title I of the Elementary and Secondary Education Act provides critical financial assistance to local educational agencies and schools with high percentages of children from low-income families that ensure all children meet challenging state academic standards. Currently, there are over 600,000 Native students across the country with nearly 93 percent of those students attending non-federal institutions, such as traditional public schools in rural and urban locations. A drastic increase in funding to counter annual inflation and sequestration is necessary to meet the needs of Native students and students from low-income families.

Impact Aid - Provide $2 billion for Impact Aid, Title VIII of the Elementary and Secondary Education Act (ESEA).

Impact Aid provides direct payments to public school districts as reimbursements for the loss of traditional property taxes due to a federal presence or activity, including the existence of an Indian reservation. With nearly 93 percent of Native students enrolled in public schools, Impact Aid provides essential funding for schools serving Native students. In Fiscal Year 2014, Impact Aid saw an increase of $64 million over Fiscal Year 2013 that restored most of the destructive sequestration cuts tribal communities faced in Indian Country. In order to ensure Native students have access to education, however, Impact Aid must be fully funded at $2 billion. Furthermore, Impact Aid should be converted to a forward-funded program to eliminate the need for cost transfers and other funding issues at a later date.

Title VII (Indian Education Formula Grants) - Provide $198 million for Title VII of the ESEA.

This grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards and attain equity with their non-Native peers. Title VII provides funds to school divisions to support American Indian, Alaska Native, and Native Hawaiian students in meeting state standards. Furthermore, Title VII funds support early-childhood and family programs, academic enrichment programs, curriculum development, professional development, and culturally-related activities. Currently, funding for Title VII only reaches 500,000 Native students leaving over 100,000 without supplementary academic and cultural programs in their schools.

State-Tribal Education Partnership (STEP) Program - Provide $5 million for the State-Tribal Education Partnership Program.

Congress appropriated roughly $2 million dollars for the STEP program to five participating tribes in FY 2012 and FY 2013 under the Tribal Education Department appropriations' line that is administered by the Department of Education. In order for this program to continue to succeed and thrive, it must receive its own line of appropriations in FY 2015. Collaboration between tribal education agencies and state educational agencies is crucial to developing the tribal capacity to assume the roles, responsibilities, and accountability of Native education departments and increasing self-governance over Native education.

Alaska Native Education Equity Assistance Program - Provide $35 million for Title VII, Part C of the ESEA.

This assistance program funds the development of curricula and education programs that address the unique educational needs of Alaska Native students, as well as the development and operation of student enrichment programs in science and mathematics. This funding is crucial to closing the gap between Alaska Native students and their non-Native peers. Other eligible activities include professional development for educators, activities carried out through Even Start programs and Head Start programs, family literacy services, and dropout prevention programs.

Native Hawaiian Education Program - Provide $35 million for Title VII, Part B of the ESEA.

This program funds the development of curricula and education programs that address the education needs of Native Hawaiian students to help bring equity to this Native population. Where Native Hawaiians once had a very high rate of literacy, today Native Hawaiian educational attainment lags behind the general population.

Vocational Rehabilitation Services Projects for American Indians with Disabilities - Increase to $67 million and create a line-item of $5 million for providing outreach to tribal recipients.

According to the Centers for Disease Control and Prevention, approximately 30 percent of American Indian and Alaska Native adults have a disability—the highest rate of any other population in the nation.[iii] A number of issues contribute to this troubling reality, including high incidences of diabetes, heart disease, and preventable accidents. As a result, tribes have an extraordinary need to support their disabled citizens in improving their health and becoming self-sufficient. Despite this need, however, tribes have had limited access to funding for vocational rehabilitation and job training compared to states. An increase in the Vocational Rehabilitation Services Projects to $67 million would begin to put tribes on par with state governments and better equip tribes to provide supports to their disabled citizens.

CONCLUSION

Thank you for your consideration of this testimony. For more information, please contact Amber Ebarb, NCAI Budget and Policy Analyst, at aebarb@ncai.org and Cesareo Alvarez, NCAI Legislative Fellow, at calvarez@ncai.org.

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[i] National Indian Education Study 2011, NCES 2012-466. National Center for Education Statistics, Institute of Education Sciences, United States Department of Education.
[ii] School Year 2010-2011 Four-Year Regulatory Adjusted Cohort Graduation Rates, Department of Education.
[iii] Centers for Disease Control and Prevention. (2011). "Disability and Health". Retrieved on January 10, 2014, from http://www.cdc.gov/ncbddd/disabilityandhealth/data.html.

Phillip M. Gattone, President & CEO

The Epilepsy Foundation of America

Testimony – House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies

Thank you, Chairman Kingston and Ranking Member DeLauro, for allowing me to testify on behalf of the more than 2.8 million Americans living with epilepsy and their families, including my own. Specifically, I want to express my support for continued funding for critical epilepsy public health programming at the Centers for Disease Control and Prevention (CDC)), as well as funding for epilepsy research at the National Institutes of Health.

Epilepsy is the nation's fourth most common neurological disorder, after migraine, stroke, and Alzheimer's disease; making it an important public health condition. Epilepsy is a complex spectrum of disorders—sometimes called the epilepsies— that affects millions of people in a variety of ways and is characterized by unpredictable seizures that differ in type, cause, and severity. Yet living with epilepsy is about much more than just seizures. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about social situations and employment, limitations on driving, and questions about independent living. Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults.

As of 2013, the Epilepsy Foundation merged with the Epilepsy Therapy Project to create a unified organization driving education, awareness, support, and new therapies for people and families living with epilepsy. This merger brings together the mission and assets of both

organizations, including www.epilepsy.com, the leading portal for people, caregivers, and professionals dealing with epilepsy; 47 affiliated Epilepsy Foundations around the country dedicated to providing free programs and services to people living with epilepsy and their loved ones; scientific, professional, and business advisory boards comprised of leading epilepsy physicians, health care professionals and researchers, industry professionals, and investors with experience in clinical care, as well as in the evaluation and commercialization of new therapies; a track record of identifying and supporting important new science, translational research programs, and the most promising new therapies; and the Epilepsy Pipeline Conference, a leading global forum organized in partnership with the Epilepsy Study Consortium that showcases the most exciting new drugs, devices, and therapies.

The Epilepsy Foundation has long realized that epilepsy should be a priority for the federal public health system, and that public health programs can help build safer communities, end stigma and discrimination associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions. Stigma surrounding epilepsy continues to fuel discrimination and isolates people with epilepsy from the mainstream of life. Among older children and adults, epilepsy remains a formidable barrier to educational opportunities, employment, and personal fulfillment. There is a continuing need to better understand the public health impact of the condition, promote initiatives that encourage self-management, and improve mental health. Meeting these needs will help create an environment in which people will feel free to disclose their epilepsy or seizures without fear of discrimination or reprisal.

The Epilepsy Foundation was pleased to participate in the 2012 Institute of Medicine report: *Epilepsy Across the Spectrum: Promoting Health and Understanding.* We believe that many of the 13 recommendations from the report reinforce the need for public health programs that help people with epilepsy access the best care and the importance of a health care workforce that is educated about seizures and epilepsy.

The CDC is the lead federal agency for protecting the people's health and safety. It is responsible for providing credible information to enhance health decisions and for promoting health through strong partnerships. The 2012 Institute of Medicine report calls upon the CDC to continue and expand collaborative surveillance and data collection, and we strongly support this recommendation to improve epilepsy surveillance within the CDC. The report also calls on the CDC to work with the Epilepsy Foundation and its affiliates to enhance educational and community services for people with epilepsy.

The CDC epilepsy program focuses on better understanding the epidemiology and impacts of epilepsy, developing and bringing interventions to the public that improve quality of life for people with epilepsy, and working with partners to change systems and environments to better support those living with this neurological condition. CDC collaborates with partners to improve public awareness and promote education and communication at local and national levels. Programs focus on law enforcement and emergency medical responders, school-based students and staff, seniors, unemployed and underemployed adults, and underserved minorities living with epilepsy.

The Epilepsy Foundation strongly believes that not only should the CDC program maintain its current funding to continue the quality programs that help address care and eliminate stigma, but also that is should receive additional funding to fulfill the recommendations and the investment of the IOM report and take advantage of the research and guidance that the report provides.

The Epilepsy Foundation understands the financial constraints facing our nation today. We encourage Congress to continue funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention. We also urge Congress to not abandon research initiatives that have been partially funded at the National Institutes of Health, and to support funding for a cure and better treatments for epilepsy.

Thank you for your consideration of this critical issue.

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Testimony of

Frank G. Zalom, PhD, President

Entomological Society of America

On

Fiscal Year 2015 Appropriations for the National Institutes of Health and Centers for Disease Control and Prevention

Submitted to the

Appropriations Subcommittee on Labor, Health and Hnman Services, Education, and Related Agencies

United States House of Representatives

March 28, 2014

The Entomological Society of America (ESA) respectfully submits this statement for the official record in support of funding for insect-borne disease research at the U.S. Department of Health and Human Services (HHS). **ESA requests a robust fiscal year (FY) 2015 appropriation for the National Institutes of Health (NIH), including increased funding for insect-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports increased investment in the core infectious diseases budget and the global health budget within the Centers for Disease Control and Prevention (CDC) in order to fund scientific activities related to vector-borne diseases.**

Advances in the biological sciences, including the field of entomology, help to address some of our most pressing societal needs related to environmental and human health. Certain species of

insects carry, spread, and transmit an array of infectious diseases that threaten populations across the globe, including those in the United States as well as U.S. military personnel undertaking missions abroad. Insect-borne diseases can present an especially challenging health problem; few vaccines have been developed against them, and insects are often difficult to control and can develop resistance to insecticides. The risk of emerging infectious diseases grows as global travel becomes easier and environmental factors continue to change. For example, West Nile virus, which is transmitted by mosquitoes and was not present in the U.S. before 1999, infected 5,674 Americans in 2012.[1] Entomological research to understand the biological relationship between insect vectors and the infectious diseases they carry – such as dengue, malaria, West Nile virus, and Lyme disease – can significantly contribute to our ability to monitor and predict outbreaks, prevent disease spread and transmission, and more reliably diagnose and treat infection. **Given the important role that insect vectors play in impacting human health, ESA urges the subcommittee to support vector-borne disease research programs that incorporate the entomological sciences as part of a comprehensive approach to addressing infectious diseases.**

NIH, the nation's premier medical research agency, advances human health by funding research on basic human biology and disease and the development of prevention and treatment strategies. In FY 2012, about 84 percent of NIH funding was competitively awarded to scientists at approximately 2,500 universities, medical schools, and other research institutions across the nation. As one of NIH's 27 institutes and centers, NIAID conducts and supports fundamental and applied research related to the understanding, prevention, and treatment of infectious,

[1] CDC DVBD factsheet: http://www.cdc.gov/ncezid/dvbd/pdf/dvbd_factsheet.pdf.

immunologic, and allergic diseases. One example of NIAID-funded research on infectious diseases is a recent study examining the mechanism by which certain species of mosquitoes known to transmit dengue and malaria are attracted to humans. The scientists discovered that specific types of nerve cells in the insects act as sensitive detectors of human odors. With this knowledge, the researchers were able to identify safe and natural chemical compounds with the potential to neutralize or overwhelm the specific insect nerve cells, a discovery that could have implications for the control of mosquitoes and their associated diseases.[2] In another recent study supported by NIAID, researchers determined that live, disease-free ticks can be used as a safe tool for testing for the presence of Lyme disease bacteria in patients who have completed antibiotic therapy.[3] **To ensure funding for future groundbreaking projects like these, ESA requests increased funding for NIAID and encourages the committee to support insect-borne disease research at NIH.**

CDC, serving as the nation's health protection agency, conducts science and provides health information to prevent and respond to infectious diseases and other global health threats, whether naturally arising or related to bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) seeks to protect our nation from the threat of viruses and bacteria transmitted primarily by mosquitoes, ticks, and fleas. DVBD's mission is carried out by a staff of experts in several scientific disciplines, including entomology. For

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[2] Tauxe, GM, et al. *Targeting a dual detector of skin and CO2 to modify mosquito host seeking.* Cell (2013).

[3] Marques, A, et al. *Xenodiagnosis to detect Borrelia burgdorferi infection: A first-in-human study.* Clinical Infectious Diseases (2014).

example, among the activities supported by DVBD are the ArboNET surveillance system for mosquito-borne diseases and the TickNET system for tick-borne diseases. ArboNET is a nationwide network that monitors West Nile virus and other diseases through activities such as the collection and testing of mosquitoes, and TickNET is a partnership between 16 states to track tick-borne-diseases like Lyme disease and test preventions. Furthermore, a component of CDC's global health budget supports activities on parasitic diseases and malaria; this includes the maintenance of a global reference insectary that houses colonies of mosquitoes from around the world to be used by the agency for studies on malaria transmission. **Given the important contributions of CDC, ESA requests that the committee provide increased support for CDC programs addressing vector-borne diseases and malaria.**

ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. Founded in 1889, ESA has nearly 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists.

Thank you for the opportunity to offer the Entomological Society of America's support for HHS research programs. For more information about the Entomological Society of America, please see http://www.entsoc.org/.

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Written Testimony of Chairman Dave Lopeman, Squaxin Island Tribe
Submitted to the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee
On the Fiscal Year FY 2015 Budget for the
Substance Abuse and Mental Health Services Administration
March 28, 2014

On behalf of the Tribal Leadership and members of the Squaxin Island Tribe, I am honored to submit our recommendation to this Subcommittee for appropriations to address the un-funded needs of American Indian and Alaska Native Treatment (AI/AN) Centers. The alarming statistics of increased alcohol and substance abuse use in the AI/AN communities speaks volumes to the need for improved and additional facilities to provide treatment and recovery opportunities to our citizens, our youths, our future leaders and the next seven generations. Although SAMHSA has limited discretionary funding and even less resources for residential care facilities, the Indian Health Service cannot keep pace with the growing need for these treatment centers. The only funding opportunity available in SAMHSA is the Treatment for Pregnant and Postpartum Women. **In 2015, we respectfully request the Subcommittee:**

1. **$10 million** - Expand access to residential care facility appropriations to include Treatment Centers and increase the annual appropriations to supplement inadequate funding for these centers from the Indian Health Service of which the NWITC will receive $1.5 million;
2. **$50 million** - SAMHSA's Behavioral Health Tribal Prevention Grant Program; and,
3. **$15 million** - SAMHSA for Behavioral Health

The Squaxin Island Tribe has been operating the Northwest Indian Treatment Center (NWITC) since 1994. Ingenious in creativity, the center offers a wide variety of cultural activities and traditional/religious ceremonies, making it a natural place to heal - body, mind and soul. Fittingly, the center was given the spiritual name "D3WXbi Palil" meaning "Returning from the Dark, Deep Waters to the Light." NWITC is a residential chemical dependency treatment facility designed to serve American Indians from Tribes located in Oregon, Washington and Idaho who have chronic relapse patterns related to unresolved grief and trauma. NWITC is unique in its integration of Tribal cultural values into a therapeutic environment for co-occurring substance abuse and mental health disorders. It is a 28 bed, 30-60 day residential facility.

Welcomed and hailed by Tribal Leaders who felt the urgent need for such a facility, NWITC is centrally located in Grays Harbor County between Olympia and Aberdeen, on 2.5 acres in the small rural town of Elma, Washington. NWITC accepts patients that are referred through outpatient treatment programs, parole and probation services, hospitals, assessment centers and child and family service centers. Medical care is provided through local Indian Health Service clinics and other medical service providers. NWITC has responded with an overwhelming success rate of nearly 65 percent.

Since the original Congressional set-aside in 1993, NWITC has not received an adequate increase in the base Indian Health Service budget. It is critical to increase the NWITC's annual base in order to sustain the current services to the Tribes of the Northwest. An increase of $1.5 million would restore lost purchasing power and meet the need to add mental health and

psychiatric components to the treatment program. This increase would allow NWITC to continue its effective treatment of Native Americans.

In 2011, the NWITC served 225 patients from 28 Tribes and added intensive case management and crisis support to alumni in order to continue to promote positive outcomes for clients. Despite funding challenges, NWITC has continued to develop and deliver innovative, culturally appropriate services to meet increasingly complex demands.

The Treatment Center's traditional foods and medicines program is supported through a partnership with the Northwest Indian College and is funded through grants from the Washington Health Foundation, the National Institute of Food and Agriculture, The Potlatch Fund and several Tribes. Weekly hands-on classes focus on traditional foods and medicines, including methods for growing, harvesting, processing, and preparation. Twice a month, Tribal elders, storytellers, and cultural specialists speak as part of the program. A monthly family class allows patients to share what they are learning with their loved ones. Patients gain hands-on experience by working in three on-site teaching gardens. This program serves as a model for other Tribal communities.

$50 million - SAMHSA Behavioral Health Tribal Prevention Grant Program

The Behavioral Health Tribal Prevention Grant will support behavioral health services that promote overall mental and emotional health, specifically substance abuse prevention and suicide prevention services. If funded, the grant program would be the only source for Federal substance abuse and suicide prevention funding exclusively available to Tribes.

$15 million - SAMHSA for Behavioral Health

This SAMHSA grant program has been authorized to award grants to Indian health programs to provide prevention or treatment of drug use or alcohol abuse, promotion of mental health, or treatment services for mental illness. To date, these funds have never been appropriated. An appropriation of $15 million would provide support to Indian health programs to meet the critical substance abuse and mental health needs of our citizens.

Self-Governance - An Efficient and Effective Use of Federal Funds (Title VI of the ISDEAA)

Self-Governance is the most successful policy in the history of Tribal – Federal relations and it inspires efficient and effective government spending. Through Self-Governance, Tribes are empowered, as sovereign nations, to exercise self-determination and to design facilities, manage programs and funds, and provide services that are responsive to the needs of our communities and Tribal citizens. Tribes participating in Self-Governance have become successful in the business of healthcare and perform several key roles, serving as, governments, employers, healthcare providers and patients.

Self-Governance Tribes have made every attempt to be innovative to operate successful health programs given the budget constraints and cuts Tribal programs have incurred the past two decades. For more than a decade we have made every effort to expand Self-Governance to other programs and our efforts to seek expansion of the program will continue until we achieve our goal. We request that this Committee recognizes the success of Self-Governance and encourage

HHS to work with Tribes to make the most efficient and effective use of Federal appropriations to fund Tribal programs.

Thank you for this opportunity to submit written testimony.

Testimony

submitted by

Dr. Irving McPhail, President and CEO

National Action Council for Minorities in Engineering, Inc. (NACME)

to the

House Labor, Health and Human Services, Education and Related Agencies

Appropriations Subcommittee

for

March 25, 2014 Hearing Record

On behalf of the National Action Council for Minorities in Engineering, Inc. (NACME), I am pleased to submit testimony to Chairman Kingston, Ranking Member DeLauro and other distinguished Members of the Committee. Our mission at NACME is to ensure American Competitiveness in a flat world by leading and supporting the national effort to expand U.S. capability through increasing the number of successful African Americans, American Indians, and Latino young women and men in science, technology, engineering, and mathematics (STEM) education and careers.

We seek funding and support for Department of Education programs that will address STEM Innovation Networks in the Fiscal Year 2015 budget, as well as support for other programs for diverse students, schools and networks across the education spectrum.

NACME's partners include *Fortune* 500 companies and nearly 51 of the nation's top educational institutions. We are led by a blue-ribbon board of directors made up of executives from 37 world-class companies and four education-based organizations.

For four decades, we have focused on the needs and interests of underserved and underrepresented populations in the STEM fields. We are the largest private provider of

scholarships in engineering for underrepresented minority students and we are the leading source of research information on the status of minorities in engineering education and employment. We are now also taking an active role in the formulation of policy positions for improving opportunities for underrepresented minorities in STEM.

With funding from individual and corporate donors, including some of the biggest and most influential companies in STEM, NACME has supported more than 23,000 students with more than $124 million in scholarships and other support. We currently have more than 1,300 scholars at 51 partner institutions across the United States, including the Midwest (Illinois, Wisconsin, Missouri, Ohio, Kansas, Oklahoma); Northeast (Connecticut, New York, New Jersey, Pennsylvania, Maryland); Southeast (Florida, Louisiana, Georgia, North Carolina, Puerto Rico, Tennessee, Alabama, Arkansas, Virginia, West Virginia); Southwest (Arizona, Texas); and West (California, Alaska, Colorado, Washington).

Our vision is an engineering workforce that looks like America. If we are to achieve this vision, more must be done to substantially increase the number of African Americans, American Indians, and Latinos pursuing college degrees in the STEM fields. Because underrepresented minorities account for only 13 percent of new engineers each year, yet account for 34 percent of all 18 to 24-year-olds, greater emphasis must be placed on improving the academic performance of underrepresented minorities completing the baccalaureate degree in engineering.

As you know, this is a critical time for our nation. Whereas 40 years ago, American corporations competed with one another, today's competition is on a global scale. Among other things, corporations that depend upon a position of leadership in research and development in the STEM disciplines must confront the reality that the sources of brainpower needed to maintain their preeminence are changing, and that new and creative approaches will be required to ensure an adequate talent pool in the future. Given the tremendous progress in science and technology

that is taking place in developing countries, the shortcomings of our public education systems, and the historic underrepresentation of sizable elements of our population, our nation must act quickly to maintain a strong position of leadership in the STEM disciplines and to ensure a future of prosperity and security.

Unfortunately, there are many people in America for whom participation in science and engineering has been, and continues to be, less likely–and their numbers are growing dramatically. In addition, diversity of experience and background also lends itself to a diversity of thinking and problem solving approaches, and strengthens the domestic capacity for innovation in the hard sciences. In the numerous calls for immediate, strong, and broad action to address the identified problems, too little attention has been given to the recognition that steps to increase the presence of underrepresented minorities in the study of STEM courses could represent a part of the ultimate solution to the issue of the dwindling cohort of students entering the fields of science and engineering.

Reports from a number of government agencies including the President's Committee on Advisors in Science and Technology (PCAST) have identified the need to diversify the STEM workforce and suggested models for accomplishing this goal. In February 2012, the PCAST report urged that the math gap in postsecondary mathematics education be addressed by the Department of Education and the National Science Foundation (NSF). The gap noted was particularly apparent in community colleges that enroll 49 percent of African Americans, 56 percent of Latinos, and 42 percent of American Indians, the groups most underrepresented in engineering.

NACME has learned that achieving success and increasing underrepresented minority participation in engineering study requires a multifaceted strategy. Scholarship support is critical, but a comprehensive engineering student support strategy that creates a supportive academic

community while promoting a high level of collaborative learning and group study is also needed. Through our partnerships, we have leveraged our scholarship grants with institutional activities that provide academic, as well as intellectual support, including: mentoring; peer tutoring; internship experiences; supplemental instruction, and bridge programs to improve minority students' preparation for pre-requisite mathematics and science courses prior to enrolling in engineering.

We have launched regional pilots in Texas and New York/New Jersey to implement the NACME STEM Integration Model (NSIM) examining methods to increase the number of minorities in the STEM pipeline.

While supporting college students is our core objective, we also recognize the necessity of recruiting students onto the STEM pathway early. This is why NACME partnered with the National Academy Foundation (NAF) and Project Lead The Way (PLTW) to launch the Academies of Engineering, a NAF network of career-themed academies designed to provide participating students with a strong science and math education so that they will be college-ready for engineering study. By involving parents, community resources, local corporations and higher education institutions (two-year and four-year), it is expected that they will have the potential of dramatically increasing the numbers of underrepresented minorities prepared to engage in engineering education.

Through the NSIM, NACME is integrating program elements into a unified continuum that leverages existing partnerships for students to move along the NACME Continuum. Students will be able to transition from the AOEs to NACME Partner Institutions and their linkage to Community Colleges; to the Alfred P. Sloan Foundation Minority Ph.D. and Sloan Indigenous Graduate Partnership Programs; or as NACME Scholars to board companies for hands-on engineering experience in a summer internship or a full-time position.

I understand the budget pressures that the Subcommittee faces as you develop this year's bill. I urge you to ensure that the government continues to be an integral partner with corporations and nonprofits in addressing many of the challenges I have identified in my testimony. Leveraging public support with private investment holds one of the most promising paths to rapidly addressing this problem facing educational achievement and corporate innovation. Many of these public private partnerships are driving initiatives across the country to recruit and train teachers, spur curriculum improvements, and increase the ranks of students studying STEM, from grade school to graduate school. By putting in place the appropriate funding and programs that provide STEM education and training for our underserved talent pool, we ensure that we will have the intellectual capital to reinforce our nation's position as the world's strongest economy and source of cutting-edge technology and innovation. I encourage the Subcommittee to support funding for education programs that advance underrepresented minorities in the STEM fields at the Department of Education. We urge support for the STEM Innovation Networks in the Fiscal Year 2015 budget proposal, as well as support for other programs for diverse students, schools and networks across the education spectrum. NACME thanks the Committee members for your support of STEM programs within the Department of Education.

NICWA
National Indian Child Welfare Association

U.S. House of Representatives
Committee on Appropriations, Subcommittee Labor, Health and Human Services, Education, and Related Agencies
National Indian Child Welfare Association FY 2015 Testimony

The National Indian Child Welfare Association (NICWA) is a national American Indian/Alaska Native (AI/AN) nonprofit organization. NICWA has over 35 years of experience providing leadership in the development of public policy that supports tribal self-determination in child welfare and children's mental health systems. We urge Congress, as they make budgetary decisions for FY2015, to not forget the unique interest of AI/AN children and families. This testimony will provide recommendations for the following programs administered by the Department of Health and Human Services: Promoting Safe and Stable Families ($75 million discretionary; $345 million mandatory), Child Welfare Services ($280 million), Programs of Regional and National Significance: Children and Family Programs ($6.5 million), and Children's Mental Health Services Program: Children's Mental Health Initiative ($117 million).

Child Welfare

Tribes have an important relationship with their children and families: they are experts in the needs of AI/AN children, best suited to effectively serve those needs, and most able to improve child welfare outcomes for these children (NICWA & Pew Charitable Trust, 2007). In addition, statistics show that AI/AN children face elevated rates of child abuse and neglect (Dept. of Health and Human Services, 2012). The key to successful tribal child welfare is a budget that avoids unnecessary restraint on tribal decision-making and accounts for the elevated need.

Priority Programs:

Child Welfare Services Program ***recommendation****: Restore funding to at least $280 million, to increase funding for tribal programs while still providing for an increase in state funding.*

This program provides funds to promote program flexibility and fill gaps in child welfare programming. Tribes receive an allocation based on a population-based formula identified within

the regulations. This tribal allocation is then deducted from the state's allocation. Studies show that culturally competent programs, resources, and case management result in better outcomes for AI/AN children and families involved in the child welfare system (Red Horse, Martinez & Day, 2001). However, without adequate funding AI/AN children and families in tribal communities cannot receive the care they need and remain at risk of further harm and trauma. Of the 566 federally recognized tribes 180 depend on this funding. The median tribal grant is about $13,300 an insufficient amount to support all the gaps in tribal services this program can fill. Because of the way the formula for tribal grants has been created, it is essential to increase the entire appropriation of this program to $280 million to increase tribal amounts.

Promoting Safe and Stable Families recommendation: *Increase discretionary funding to $75 million to allow more tribes, who are currently ineligible, access to these funds. As recommended by the President fully fund the $345 million in mandatory funding cut due to sequestration.*

This program is designed to provide funds to operate a coordinated program of family preservation, family support, reunification, and adoption support. Promoting Safe and Stable Families is authorized with both a mandatory capped entitlement ($345 million) as well as a discretionary appropriation ($200 million). Tribes are eligible for funds based on a 3% set-aside of the total appropriation. Tribal child welfare programs work tirelessly to strengthen families and provide services that keep children safely in their homes. This program is an integral part of these efforts. It supports parenting classes, home-visiting services, respite care for caregivers of children, and other services that safely preserve families. One hundred and thirty tribes and tribal consortia depend on this funding. Yet because of the funding levels, many tribes are ineligible for these formula grant dollars because their portion of the tribal set-aside is less than $10,000.

Increasing this program's discretionary funding to $75 million and fully funding the $345 million in mandatory funding could help dozens of new tribes access this funding and help hundreds of families obtain tribal services to avoid out-of-home placement of their children.

Other Recommendations:

Child Abuse Discretionary Activities, including Innovative Evidence-Based Community Prevention Programs recommendation: *Increase appropriations to $35 million to account for tribes' recent eligibility for these funds while holding state and other grantees harmless.*

The Community Based Child Abuse Prevention Program recommendation: *Increase funding to $60 million, so that more tribes can have access to these scarce child abuse prevention dollars.*

Demonstration to Address Over-Utilization of Psychotropic Medications for Children in Foster Care recommendation (Presidents FY 2015 Initiative): *Fund this initiative at the proposed $250 million and ensure a tribal set-aside of 3% so that tribal communities can also participate in this important initiative to ensure children receive holistic mental health care.*

Children's Mental Health

To understand the mental health needs of AI/AN children, policymakers must consider the legacy of trauma that has been visited upon this population and left them with unresolved historical trauma (Yellow Horse Brave Heart and DeBruyn, 1998). Inadequate funding, uncoordinated health systems, cultural incompetence, and a shortage of mental health professionals are barriers to the development of successful mental health systems of care in AI/AN communities (Novins & Bess, 2011). Key to children's mental health programs in tribal communities, is a budget that supports and strengthens a system of tribally driven children's mental health prevention, intervention, and treatment.

Priority Programs:

Programs of Regional and National Significance: Children and Family Programs (Circles of Care) recommendation: *Fund Circles of Care Program at $6.5 million as recommended by the President to ensure current communities can continue their important work and new tribal communities can have access to this program.*

The Children and Family Programs line item represents funds allocated to the Circles of Care Program—which is the cornerstone of tribal children's mental health programming. The Circles of Care program is the only SAMHSA grant program that is focused specifically on AI/AN children's mental health needs. It is also the only SAHMSA program that allows tribes and tribal organizations to apply without competing for funding with other governmental entities such as states, counties, or cities. There are currently seven communities receiving Circles of Care funding. The American Psychiatric Association has found that AI/AN children and youth face a "disproportionate burden" of mental health issues while simultaneously facing more barriers to quality mental health care (2010). Programs like Circles of Care, which provide communities with funding to plan and build culturally competent services and design integrated supports that meet the specific needs of their youth with behavioral health challenges, are, therefore, essential to the well-being of AI/AN youth today. It is imperative that funding that matches the President's request of $6.5 million be reserved in this line item for the Circles of Care program to ensure more tribal communities can have access to this grant to improve their children's mental health care systems.

Children's Mental Health Services Program: Children's Mental Health Initiative (Systems of Care) recommendation: *Maintain funding at $117 million to continue support of Tribal children's mental health systems change.*

The various Systems of Care grants funded under this line item support a community's efforts to plan and implement strategic approaches to mental health services and supports that are family driven; youth guided; strength based; culturally and linguistically competent; and meet the intellectual, emotional, cultural, and social needs of children and youth. Currently, 17 tribal communities are funded under the Children's Mental Health Initiative line item. The American Psychiatric Association (2010) has recognized family, culture, and traditional health practices as important protective factors for AI/ANs struggling with mental health challenges. The Systems of Care program has been both well-received and particularly effective in tribal communities. The well-being of AI/AN children is dependent on the ability of more tribes to access these funds and create real systems change. Thus, funding must be maintained at $117 million as recommended by the President. This will ensure the current Systems of Care grantees can continue, and a new robust cohort of grantees can begin this important work.

Other Recommendations:

Tribal Behavioral Health Grants recommendation: *Implement President's Budget FY2013 recommendation to fund this new initiative at $40 million so that additional tribal communities can receive resources for children's mental health and substance abuse.*

The GLS State/Tribal Youth Suicide Prevention and Early Intervention Program recommendation: *Keep funding at the FY2014 appropriated level of $35.5 million to ensure that current grantees can complete their projects, and a similar sized cohort of annual grantees will have access to this program.*

The AI/AN Suicide Prevention recommendation: *Fund at the President's proposed amount of $2.94 million, to ensure that the epidemic of AI/AN suicide receives the attention it warrants.*

If you have any questions about this testimony please contact NICWA Government Affairs Associate Addie Smith at addie@nicwa.org or (503) 222-4044 ext. 134.

Testimony of Thomas Caprio, MD, MPH, FACP
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Submitted for the Record to the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies – Public Witness Hearing March 25, 2014

The National Association for Geriatric Education (NAGE) is pleased to submit this statement for the record recommending **$41.997 million in Fiscal Year 2015 to support geriatrics programs** under the Health Resources and Services Administration (HRSA), Title VII, Section 753 of the Public Health Service Act. NAGE respectfully requests that the Subcommittee return to its approved level for FY 2010, which was also included that year in the Administration's request, but was not included in the final bill. Unfortunately, only $34 million was funded in the final bill, and that has been cut to under $34 million in subsequent years.

NAGE is a non-profit membership organization representing Geriatric Education Centers (GECs) and other programs that provide education and training to health professionals in the areas of geriatrics and gerontology. Our mission is to help America's health workforce be better prepared to render age-appropriate care to today's older Americans and those of tomorrow.

NAGE recognizes the Subcommittee faces difficult decisions in a constrained budget environment, a continued commitment to programs supporting the growing need for geriatric education programs that help the nation's health professions better serve the older and disabled population should remain a top priority. The nation faces a shortage of geriatric health professionals. Every day in America 10,000 more persons reach the age of 65 years. There

simply are not enough geriatricians, gerontological nurse practitioners and the myriad other health professions needed to provide interprofessional care to this burgeoning older population.

Three geriatric health professions programs are financed under Title VII, Section 753 of the Public Health Service Act and are included in the Health Resources and Services Administration (HRSA). Geriatric Education Centers (GECs) and their related programs, the Geriatric Academic Career Awards and the Geriatric Faculty Fellowships, provide much needed interdisciplinary geriatric and gerontology training to a broad range of health professionals who serve our rapidly growing aging population.

GECs train health care professional faculty, students, and practitioners in the interprofessional diagnosis, management and prevention of disease, disability, and other health problems of the elderly. This program also provides interprofessional continuing education for health care practitioners related to prominent issues in the field of geriatrics, such as Alzheimer's disease, dementia, and advances in palliative care, among others. The GEC program currently funds 45 GECs in 34 states, including statewide and multi-state programs. About half of GECs provide education for areas that are more than 50% rural and one-fourth of GECs focuses on training in areas that are 25-49% rural. In the 2012-2013 Academic Year, GEC programs provided over 1,650 different continuing education courses to over 94,000 trainees. GEC grantees exceeded the program's performance goal by 58.5%.

Geriatrics Training for Physicians, Dentists, and Behavioral/Mental Health Professionals (GTPD) support faculty fellowships that help physicians, dentists, and behavioral and mental health professionals who plan to teach geriatrics in their selected fields. The aim of the program is increase the number of quality, culturally competent geriatric faculty and to retain mid-career

faculty in geriatrics. GTPD provided funding for 64 fellows in the academia field of geriatric medicine, dentistry, and psychiatry. The GTPD fellows received clinical training in over 200 different health care locations across the nation. The majority were trained in Veteran's Affairs hospitals, private hospitals and academic centers with nearly half of the sites located in medically underserved communities. Notably, each fellow dedicated at least 25% of their time for teaching health students about geriatric-related topics. In Academic Year 2012-2013, it is estimated that over 275 courses, workshops and other activities were delivered by GTPD fellows.

Geriatrics Academic Career Awards (GACAs) provide a financial incentive for junior faculty to pursue an academic career in geriatrics. GACA currently supports 62 newly trained geriatric physicians. Award recipients delivered over 1,110 different health courses, workshops and other types of training activities to over 53,000 trainees across the health profession spectrum. The most common health professions include medical school students, residents in internal medicine and residents in geriatrics.

These successful programs improve the education, supply, distribution, diversity, and quality of health care professionals who care for our nation's growing older adult population, including the underserved and minorities. Thus, we need your continued support for geriatric programs to adequately prepare the next generation of health professionals for the rapidly changing and emerging needs of the growing and aging population.

On behalf of NAGE, thank you for this opportunity to share our requests for support for these important programs. We ask that you thoughtfully consider our request for funding in FY 2015.

Yasmina Vinci
Executive Director, National Head Start Association
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Department of Health and Human Services, Head Start and Early Head Start

Chairman Kingston, Ranking Member DeLauro, thank you for allowing the National Head Start Association (NHSA) to submit testimony on behalf of funding for Head Start and Early Head Start in Fiscal Year 2015 (FY15). For almost 50 years, Head Start centers have been creating opportunities for at-risk children and families to achieve success in life by providing critical early education, health, nutrition, parent engagement and family support services. NHSA respectfully urges the Subcommittee to continue its enduring bipartisan support by allocating $8,868,389,000 for Head Start and Early Head Start in FY15, in line with the President's Budget.

Head Start and Early Head Start directors remain appreciative of your leadership in ensuring that the FY14 Omnibus Appropriations legislation not only restored the damaging cuts from sequestration, but also prioritized high quality by including additional funds to retain qualified staff and cope with the increased costs of program operation. We also sincerely appreciate the new investment in one of our most underserved populations—low income infants and toddlers.

Within the total amount of funding for FY15, we urge the Subcommittee to continue and build on these investments. In particular, we propose a $150 million increase to support workforce quality improvements and to help offset the continued rise in energy, transportation, and other fixed costs related to operating a Head Start program. It is well known that one of the hallmarks of excellence in any early learning program is the caliber of its teachers. Head Start teachers are required to possess Bachelor's degrees in early learning or related fields, which enables the program to have one of the best-trained workforces in the country. However, the average salary

for these degreed teachers is $30,086 – lower than what many schools pay teachers, and much lower than salaries for many other jobs with comparable education requirements.

Examples of programs losing their best staff to higher paying schools or other providers are plentiful across the country. In New York, one Head Start social/emotional education mentor-coach reported seeing several "gifted teachers, assistants and aides leave our classrooms after short stays due to the pressure to provide for their own families." Many of the staff that do choose to stay with Head Start struggle to make ends meet – such as the Oregon teachers who have depended on a local food bank to help feed their own children. Focusing increased investment toward workforce quality improvements will help enable programs to hold on to dedicated teachers, and provide a solid foundation for the good of our students and families.

Supporting a High-Quality Birth-to-Five Pipeline: NHSA also urges the Subcommittee to support the continued development of a birth-to-five pipeline of services through expanded access to Early Head Start, which today is only able to serve a scant 4% of eligible infants and toddlers. Continued early brain research tells us that with the achievement gap present as early as 18 months, these first two years of life represent a critical window in development. Early Head Start centers are among the highest quality environments for children of this age. We propose that the Subcommittee continue to fund the new Early Head Start-Child Care Partnerships at $500 million. These funds should, as in FY14, support the straight expansion of Early Head Start as well as partnerships with Child Care providers, ensuring programs designed by and solely based on the needs of individual communities.

We are aware of many underserved areas with few options for partnerships — these communities should be given as much flexibility as possible to increase access to high-quality care. For

example, Audubon Area Community Services, Inc. in Kentucky serves a 16 county area. However, even though there are an estimated 17,911 children in their service area that are eligible for Early Head Start, they are only funded to serve 301 Early Head Start slots. In two of those 16 counties, there are 600 eligible children but no licensed child care facilities with which to partner. In yet a third county, there is licensed child care but no infant/toddler care. With flexibility to invest in expansion, they could find a way to serve those areas.

Further, NHSA also urges the Subcommittee to allocate $100 million to fund the expansion of the Birth-to-Five pilot programs that the Office of Head Start (OHS) began last year in Detroit, Baltimore, Jersey City, Washington, DC, and Mississippi's Sunflower County as part of the first Designation Renewal System (DRS) recompetition. The grants are meant to encourage applicants to develop comprehensive, flexible, seamless Birth-to-Five programs which incorporate both Head Start and Early Head Start funding. We hope the Subcommittee will recognize the value of this approach and support expansion of these models outside of DRS. In particular, we suggest that the Administration utilize a portion of the funds to create a process that enables current grantees that hold both types of grants to streamline the administrative burden and combine these two grants into one.

These Birth-to-Five expansion funds should also be used to assist Head Start grantees to add Early Head Start slots and convert existing Head Start slots for 3-4 year olds to Early Head Start slots; both actions support the goal of providing an Early Head Start slot to complement each Head Start slot. Across the country, as states and localities both expand and contract services for infants, toddlers, and preschoolers, Head Start programs have the necessary skills to adapt their

services to fit the changing needs of their community. But as resources shift, additional funding to help transition to new or different types of slots would be a welcome support.

Ongoing Quality Improvements: Robust funding will ensure that key quality improvement initiatives continue at OHS. In particular, OHS should finalize an update to our rigorous performance standards as mandated in the 2007 Head Start Reauthorization Act. Serious and meaningful efforts are underway to ensure that the standards are modernized to reflect the needs of today's children, families, teachers, and communities—while allowing for innovation and local adaptability.

Further, we are hopeful that OHS is able to continue improvements to the Head Start Monitoring System—the oversight mechanism that ensures grantees meet performance standards. We are pleased that OHS has instituted new initiatives that aim to work with programs to prevent issues before they occur, and that they are enabling iterative feedback and data collection to better target assistance and intervention where programs require it most.

Regarding the Designation Renewal System, the accountability measure that requires Head Start grantees designated as low-performing to compete for the continuation of their grant, NHSA supports the Administration's request for $25 million to assist with grantee transition costs in the event that a grant turns over, though NHSA remains concerned these competitions are unintentionally poorly timed. Currently, the results of grant competitions are not determined until late in the summer. With a school year beginning shortly thereafter, a new grantee taking over for a low-quality incumbent faces a steep climb to recruit teachers, enroll children, and prepare facilities. This is an avoidable strain on communities. Considering the opportunity that DRS

provides to improve program quality, we hope the Subcommittee supports the resources needed to ensure that these competitions are run effectively and efficiently, and that the process is accurately capturing programs that are of low quality.

Head Start is a High Yield Investment: To take a step back, NHSA believes that the budget caps now in place limit the opportunities to make high-yield investments. President Obama proposed an additional $800 million to support Head Start and Early Head Start expansion. We appreciate the focus on the need to reach the large population of underserved, at-risk infants, toddlers, and preschoolers, but understand that new investments that exceed this year's budget caps are unlikely. Studies show that for every one dollar invested in a Head Start child, society earns at least $7 back through increased earnings, employment, and family stability;[i] as well as decreased welfare dependency,[ii] health care costs,[iii] crime costs,[iv] grade retention,[v] and special education.[vi] These are the very results taxpayers demand for their investments.

Again, the Head Start community understands the pressure the Subcommittee faces and is grateful for the commitment shown by Congress and the President to keep early learning, and Head Start in particular, as a priority. We urge the Subcommittee to build on the investments made in Head Start and Early Head Start, to increase access, to improve accountability, and ensure the prosperity of our next generation. Thank you for your time and consideration.

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[ii] Meier, J. (2003, June 20). Kindergarten Readiness Study: Head Start Success. Interim Report. Preschool Services Department of San Bernardino County.

[iii] Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06-WG01; Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? *The American Economic Review*, *85*(3): 360; Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. *Economic Inquiry*, 48 (3), 587-602.

[iv] Reuters. (2009, March). Cost of locking up Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. *American Economic Review*, 92 (4): 999-1012.

[v] Barnett, W. (2002, September 13). The Battle Over Head Start: What the Research Shows.; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-Term Effects of Head Start. *American Economic Review*, *92* (4): 999-1012.

[vi] NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). *Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services*. Office of Shared Accountability, Montgomery County Public Schools.

American Dental Education Association
Testimony for the Subcommittee on Labor, Health and Human Services, Education and Related Agencies
United States Senate

The American Dental Education Association (ADEA), on behalf of all 65 U.S. dental schools, 700 dental residency training programs, 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, submits this statement for the record and for your consideration as you begin to prioritize fiscal year 2015 appropriation requests. ADEA urges you to preserve the funding and fundamental structure of federal programs that provide prevention of dental disease, access to oral health care for underserved populations, and access to careers in dentistry and oral health services. 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. Services are provided through campus and offsite dental clinics where students and faculty

provide patient care to the uninsured and underserved populations. However, in order to continue to provide these services, there must be adequate funding. Therefore, it is critical that funding for oral health care, delivery of care, and research be preserved in order to ensure the level of care that is necessary for all segments of the population.

We are asking the committee to maintain adequate funding for the dental programs in Title VII of the Public Health Service Act; the National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR); the Dental Health Improvement Act; Part F of the Ryan White HIV/AIDS Treatment and Modernization Act: the Dental Reimbursement Program and the Community-Based Dental Partnerships Program; and State-Based Oral Health Programs at the Centers for Disease Control and Prevention (CDC). These programs enhance and sustain state oral health departments, fund public health programs proven to prevent oral disease, fund research to eradicate dental disease, and fund programs to develop an adequate workforce of dentists with advanced training to serve all segments of the

population including the underserved, the elderly, and those suffering from chronic and life-threatening diseases.

$32 million for Oral Health Training Programs

The dental programs in Title VII, Section 748 of the Public Health Service Act that provide training in general, pediatric, and public health dentistry and dental hygiene are critical. Support for these programs will help to ensure there will be an adequate oral health care workforce to care for the American public. The funding supports pre-doctoral oral health education and postdoctoral pediatric, general, and public health dentistry training. The investment that Title VII makes not only helps to educate dentists and dental hygienists, but also expands access to care for underserved communities.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general, or public health dentistry or dental hygiene. There are currently almost 200 open budgeted faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining

faculty. ADEA is increasingly concerned that with projected restrained funding, the oral health research community will not be able to grow and that the pipeline of new researchers will be inadequate to the future need.

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. For the last several years, these programs have not received adequate funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population. The ADEA is most concerned that the Administration did not request any funds for the Health Careers Opportunity Program (HCOP). This program provides a vital source of support for oral health professionals serving underserved and disadvantaged patients by providing a pipeline for such individuals from these populations to learn about careers in health care generally and dentistry specifically that is not available through other workforce programs.

$18 million for Part F of the Ryan White HIV/AIDS Treatment and Modernization Act: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program

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 (DRP) 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. DRP 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. This program, in FY 2013, only reimbursed dental schools for the unreimbursed costs at 23 percent of those costs, continuing the shift of the cost burden to the schools. This path is not sustainable to provide the necessary care. The increase requested would reimburse barely half of the dental school's incurred costs of care.

$425 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 millions of Americans, and uncovered important associations between oral and systemic health. Dental researchers are poised to make 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 (such as HIV, and certain types of cancer); 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.

Also, dental scientists 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.

$19 million for the Division of Oral Health at the Centers for Disease Control and Prevention (CDC)

The CDC Division of Oral Health 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. This strong public health response is needed to meet the challenges of oral disease affecting children and vulnerable populations.

The level of funds available in recent fiscal years are below the level needed to adequately sustain an appropriately staffed state dental program, provide a robust surveillance system to monitor and report disease, and support state efforts with other governmental, non-profit, and corporate partners. The current path of funding will continue to have a negative effect upon the overall health and preparedness of the nation's states and communities.

Thank you for your consideration of these requests. ADEA looks forward to working with you to ensure the continuation of congressional support for these critical programs.

Written Testimony for the Record

Merle Turitz, Director, RSVP of Monroe County, PA
Member of National Senior Corps Association and
National RSVP Directors Association
RSVP of Monroe County, Pennsylvania 411 Main Street Suite 102B Stroudsburg, PA 18360

Federal Funding: $78,296 with matching local funds of $49,233

March 23, 2014

To the Honorable members of the House Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies:

My name is Merle Turitz, Director of the Retired and Senior Volunteer Program (RSVP) of Monroe County, Pennsylvania, best known as The Poconos. Because of its proximity of being less than 2 hours from both New York City and Philadelphia, Monroe's population has grown by 22% in the last 10 years, becoming an extended bedroom community of the larger cities and a desirable retirement community. Services and budgets in the Poconos, have not kept pace with the population growth, so volunteer programs, like RSVP play a critical role in closing the gap between essential services for the needy and senior populations and over-extended county and state budgets. The federal funding portion for my program is $78,296 with matching local funds of $49,233. The investment of $127,529 brings the equivalent of $3.3 million dollars in donated services to this county.

These valuable and dependable services include door to door Medical Transportation for those with no other transport means, Grocery Shopping and Socialization Visits to the homebound, Tutoring to under-performing students, free tax preparation for the low income, Medicaid and Medicare benefits counseling, minor home repairs and building handicapped decks, leading exercise programs, computer training to seniors and other vulnerable populations.

In addition, our seniors are serving in the local hospitals, libraries, senior centers, personal care facilities, and other budget-strained organizations in our county.

The unique benefit of the senior corps program is two-fold one. There is no doubt that the non-profit and government agencies and their clients receive services, sometimes daily and/or weekly, that most budgets would not be able to offer. Most of these services focus on keeping clients safe and independent in their own homes, off the public welfare system. On the flip side, providing healthy, experienced and willing seniors with challenging and motivating volunteer opportunities, keeps them involved in their communities, gives them purpose and meaning, stimulates their minds and in general, keeps them healthier longer.

There is no other organized program that has such an impact across our seniors population as the RSVP programs. Multiply this by the 628 other RSVP programs, the 222 Senior Companion Programs and the 328 Foster Grandparent Programs under the Senior Corps umbrella, and you will find almost a half-million senior volunteers strong, contributing to the betterment of every urban, suburban and rural town throughout this country.

Each year, our Minor Home Repair program completes about 75 home repairs for seniors, the low income and the disabled. These little jobs, like safety bar installations, window and stair repairs, allow people to remain independent and off public housing. We build two handicapped ramps each year. Last year, the recipient, through tears of joy, hugged the RSVP Volunteers and said, "It has been three years since I've been able to get out of my house."

My files are filled with thank you notes from Seniors who have no neighbors or family to turn to who can help shop for them and stock their refrigerators. Asking for help, at any age, is not easy so when we are asked to assist with a task like helping someone with poor vision read their mail, organize their mail that overwhelms them and piles up on their desk, erect a broken

mailbox, or sit with a terminally ill patient so their full time caregiver can get some respite, or help a young pre-schooler with basic math and reading skills, we say yes. We say yes, because without our help, these lonely people have nowhere else to turn. Why else would they turn to us for assistance? But it's more than that. How about Durwood K who received a brand new IPad from his daughter for Christmas three years ago but didn't know how to use it until he received individualized training that not only upgraded his technical skill, but allowed him to Skype with his loved ones across the country. And Mrs. M, who can no longer see out of her right eye while her left eye sees at only 60%, was embarrassed to let someone see her living room and den furniture covered with unpaid bills because she had become so overwhelmed with the disorganization. One volunteer came to her home and in 30 hours over two weekends, helped her organize, file, cull and label file drawers to gain control of her life. Her gratefulness and appreciation could not be expressed except through tears. We have over a dozen disabled seniors who receive their Salvation Army and Second Harvest food distributions right to their door, delivered by RSVP volunteers who understand that these county residents are unable to stand in the long lines for food. Our Sock-It-To-Me volunteers have collected 3000 pairs of new socks to distribute to homeless and needy families through Women's Resources, Transitional Housing, Veteran's Support groups and Headstart. The program was so successful, we have expanded it to the HUGS program and we are now collecting Hats, Underwear, Gloves and Socks.

There are thousands of these stories that are shared by the directors of all RSVP, SCP and FGP programs throughout the country. The current structure of CNCS, including the current funding levels for the maintenance and continuity of the valuable Senior Corps program must be secured. Not funding Senior Corps is bad for our citizens, bad for our seniors and bad for America.

Written Testimony for the Record

On behalf of the 750 RSVP Monroe County volunteers, the 1000 of service recipients of Monroe County, the 80 non-profit organizations and government agencies served by RSVP, the local state and county funders, and myself, I urge you to stop this penny-wise, pound foolish decision to de-fund the Senior Corps and maintain its current level of funding and its structure within the Corporation for National and Community Service.

Sincerely yours in service,

Merle Turitz
Director
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Written testimony for the record
Laureen Stengler, guardian Wayne Stengler
Gary Stengler, brother
3/25/2014

House Appropriations' Labor, Health and Human Services, Education and Related Agencies Subcommittee Members:

Thank you for this opportunity to submit comments for your consideration.

We are writing to urge Congress to prohibit the use of federal Health and Human Services (HHS) appropriations in support of deinstitutionalization. These activities result in the eviction of eligible individuals with intellectual and developmental disabilities (I/DD) from their HHS-licensed and funded homes.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with this same request. We support VOR's testimony with this same request.

By funding deinstitutionalization activities the most severely multiply and intellectually disabled citizens currently served in ICF/MR facilities are forced into small community homes scattered throughout our states. This puts them at risk for abuse and neglect. Community homes do not provide Active Treatment and do not have the level of oversight required by ICF/MR regulations. Forced deinstitutionalization ultimately denies the most severely intellectually and multiply disabled the services they are entitled. This is a violation of the Americans with Disabilities Act, the Rehabilitation Act, Medicaid and a variety of other state and federal laws.

We are now in the midst of a national movement to encourage the intellectually and physically disabled to make choices and receive services in the community. We fully support this for those who are able and can benefit from this type of setting. We ask you however, to consider that there is a segment of our population that is so seriously intellectually and physically disabled that an "institutional" setting may be the least restrictive setting and the most realistic in terms of efficiency in providing essential services.

The U.S. Supreme Court Olmstead decision is often quoted and interpreted as a mandate to close all institutions. The Olmstead decision is no such mandate.
A majority of the Justices recognized an ongoing role for publicly and privately-operated institutions. "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187. Justice Kennedy noted "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be

interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." 119 S. Ct. at 2191. Yet... that is exactly what is happening.

For the past 48 years our loved one Wayne has received excellent compassionate care while residing at the Murray Developmental Center. Wayne has a mental age of 8 months and is completely dependent on others for entirely every need. He has cerebral palsy so severe that he cannot walk and must be fed. He is on a pureed diet to reduce the likelihood of aspiration. Wayne is visually and hearing impaired. He is medically fragile and requires 24 hour nursing. Wayne is repositioned every two hours which limits where he can go and for how long. He has never had a bed sore. He is unable to express his wants or needs except by grunts or groans so when he is ill the nurses must interpret his sounds and use their knowledge of him along with their expertise to determine what is going on and how to proceed. The residents have consistency and understanding as staff have worked there many years. We have met two generations of caretakers for Wayne.

Murray Center, where our loved one resides, is now slated for closure. Nearly all of the private guardians (around 200) have placed forms in our loved ones charts voicing opposition to a less restrictive setting. When public hearings are held, Illinois' Protection and Advocacy Group, Equip for Equality shows up with individuals clearly much higher functioning and able to express an opinion advocating for closure. These individuals are clearly not representative of the residents living at the centers that they are advocating for closure. Guardians have placed forms in the charts to forbid Equip for Equality from speaking with our loved ones or staff about their care as we do not believe they have the best interest of our loved ones at heart and are distrustful of their methods.

On 2/19/2013 the Murray Parents Association along with the Illinois League of Advocates for the Developmentally Disabled and many individual plaintiffs (including Laureen Stengler) filed a complaint for declaratory, injunctive and other relief against the Illinois Department of Human Services and Kevin Casey, in his official capacity as Director of Developmental Disabilities, and Community Resource Alliance. The complaint was filed with the U.S. Northern District Court in Chicago (Case 1:13-cv-01300). Rather than using the state's professionals currently working at Murray, an out of state company called Community Resource Alliance (CRA) was hired to conduct assessments for community placement into 2-4 bedroom homes. Evidence presented at trial demonstrated that this was a process that was used to recast our loved ones for placement into the 2-4 bedroom homes. There were many affidavits presented from Murray staff on the numerous problems with the process.

As the state progressed moving residents under the Office of the State Guardian (OSG) through the assessment process and ultimately into small group homes, staff became increasingly concerned about the appropriateness of the placements and

the safety of the residents already moved. Friends for Murray Center (FFMC) and several individual plaintiffs filed a request for a temporary restraining order on 7/29 2013 with the State court on behalf of those residents. A temporary restraining order was granted and is still in place as is the federal restraining order.

Stuart Freeman, a public defender was assigned to be guardian ad litem. Mr. Freeman made surprise visits to the homes of wards now under his care. He submitted an affidavit to the court on 9/23/2013 citing many problems including, inadequate security, inadequate staffing (long day and hour shifts), lack of staffing experience, lack of supplies and home support (fireproofing, padding, bedding, etc.), unsafe conditions (exposed hazards), lack of knowledge as to client care, low pay, little training and little to no decoration or personalization for the residents. He believes that some of his clients never should have been placed in community placement. Mr. Freeman fears the consequences that could happen if these conditions continue, especially after scrutiny of the facilities has passed. The State requested that Equip for Equality provide an independent review of the placements. It is perplexing to the families why this agency, clearly biased toward community placement would be asked to review the findings of an independent attorney assigned by the court. No problems were reported. This is in stark contract to Mr. Freeman's findings.

The most vulnerable among us need our protection. Public funds should not be used to force deinstitutionalization. This places our loved ones at risk for abuse and neglect. The group homes do not have the level of oversight required by the ICF/MR regulations. Developmental Centers provide essential services for the most severely intellectually and physically disabled and must continue as an option in the continuum of care.

Thank you.

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